

**National Health Information Management
Advisory Council**

**Proceedings from the
National *Health Online* Summit**

**Adelaide
3 - 4 August 2000**

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Foreword

The health sector is rapidly embracing new and evolving information and communication technologies to transform the way in which health care is delivered, with the aim of securing improved health outcomes and better quality of care for consumers.

Although such technologies offer great benefits, we run the risk that unless we can build on the myriad of projects currently planned or underway in every State and Territory, and across the private sector, we may well end up paying for substantial duplication and wasted resources.

The National Health Information Management Advisory Council (NHIMAC) was established by Australian Health Ministers in July 1998 as the peak national body to advise them on options to promote a nationally uniform approach to more effective information management within the health sector.

In November 1999, NHIMAC released *Health Online: A Health Information Action Plan for Australia*. *Health Online* is a national strategy for information management and the use of online technologies within the health sector.

Health Online maps the ways Australians will be able to use health information in the future and describes the necessary steps to get there. Importantly, *Health Online* addresses the issues of information privacy and security, which are crucial considerations in any application of information technology in the health sector.

The National *Health Online* Summit built on the themes introduced in *Health Online*, giving participants a comprehensive picture of developments in information technology across the health sector, as presented by experts in the area. The Summit also provided a report card on progress in relation to key *Health Online* themes such as electronic health records, telehealth and standards development. Importantly, the Summit outcomes will help inform the development of the second edition of *Health Online*.

I would like to thank those who participated in the National *Health Online* Summit and made it such a memorable event. I would especially like to recognise the enormous amount of work invested in the Summit by speakers, and by Irene Krauss, Cathy Tippet, and Conference Coordinators, who organised the event. The compilation of the Summit proceedings has also been a substantial undertaking. I would like to thank Irene Krauss and Cathy Tippet for their contribution in finalising what I think is a very valuable record.



Professor Richard Smallwood

Chair

National Health Information Management Advisory Council

February 2000

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Background and purpose of the National *Health Online* Summit

Health Online – A Health Information Action Plan for Australia is a landmark in health information management for Australia. It provides a strategic framework to bring together the key stakeholders in the health care system and to develop a common vision and sense of purpose. It places information management at the heart of the health system and harnesses new information technologies to improve information flow, promote continuity of care, support clinical decision making and empower consumers and communities.

The first version of *Health Online* was developed as a blueprint for progressing the health information management/information technology agenda nationally. Most importantly, it was intended to be a ‘living document’ that would be updated and refined over time.

It is this focus on an evolving approach to the national health information management agenda that gave rise to the National *Health Online* Summit. Nine months on from the publication of *Health Online*, the Summit gave us the opportunity to step back and ask - how well are we doing? What has this national collaboration achieved? Are there other priorities we should add to the list? In the ever-changing health and technology environments, what advances do we need to take into account? Are there limitations to current strategies and better alternatives for us to consider?

The *Health Online* Summit program was designed both to leave participants better informed and to elicit views on current activities and future priorities. The Summit gave participants the ideal opportunity to contribute their knowledge and views, which will be used to shape future national policy development.

This proceedings document contains many of the speeches presented at the Summit. These provide a range of views on the exciting work currently underway in the health information management area, although it should be acknowledged that these views are the authors’ own and do not necessarily represent the views of the Commonwealth Department of Health and Aged Care.

Where full speeches were not available, abstracts from the original Summit guide have been included. The proceedings will provide an excellent resource for people involved or interested in health information management and technology in Australia.

Summit program

Thursday 3 August 2000

SETTING THE SCENE

9.00 **Welcome and Opening Remarks from the Chair**

Professor Richard Smallwood, Chair, National Health Information Management Advisory Council and Chief Medical Officer, Commonwealth Department of Health and Aged Care, ACT

9.10 **Opening Address**

The Hon Dr Michael Wooldridge, Federal Minister for Health and Aged Care

9.30 **An International Perspective on Health Information Management**

Dr David Mowat, Acting Director General, Centre for Surveillance
Co-ordination, Population and Public Health Branch, Health Canada

10.25 *Morning Tea*

ADVANCING NATIONAL COLLABORATION

10.45 **A National Collaborative Approach**

Key Achievements and Future Directions

Chair: Professor Richard Smallwood, Chair, National Health Information Management Advisory Council and Chief Medical Officer, Department of Health and Aged Care, ACT

Ms Kate Moore, Consumer Representative, National Health Information Management Advisory Council, ACT

Mr Michael Reid, Chief Executive Officer, NSW Health

Mr Frank Quinlan, National Co-ordinator, General Practice Computing Group, ACT

12.00 *Lunch*

LAYING SOUND FOUNDATIONS

1.00 **Enhancing Privacy and Confidentiality in the World of E-Health**

Keeping Personal Health Information Safe

Chair: Mr Malcolm Crompton, Federal Privacy Commissioner and National Health Information Management Advisory Council member

Dr Kerry Phelps, President, Australian Medical Association, NSW

Ms Meredith Carter, Director, Health Issues Centre, Vic

Ms Helen Daniels, Assistant Secretary, Information Law Branch, Commonwealth Attorney-General's Department, ACT

2.20 *Afternoon Tea*

2.40	Setting Health Standards Terrace 1 and 2	Security and Authentication Crystal Room	Research and Development Terrace 3
	<p>Health Information Standards – Where to From Here?</p> <p>Chair: Mr Philip Hagan, Assistant Secretary, Information and Research Branch, Commonwealth Department of Health and Aged Care, ACT</p> <p>Mr Peter Williams, Chair, IT14 and Director, Information Management and Clinical Systems, NSW Health</p> <p>Dr Oliver Frank, RACGP and GPCG Representative, SA</p> <p>Ms Debra O'Connor, Consumers' Health Forum of Australia, Vic</p> <p>Dr Ric Marshall, Manager, Information and Performance Evaluation, Victorian Department of Human Services, Vic</p>	<p>Sharing Information Securely – Future Directions</p> <p>Chair: Dr Brian Richards General Manager, Information Management Division, Health Insurance Commission, ACT</p> <p>Mr John Lewis, Senior Manager, KPMG Consulting, NSW</p> <p>Professor Branko Cesnik Director, Centre for Medical Informatics, Monash University, Vic</p> <p>Dr Tom Stubbs, Chief Information Officer, SA Department of Human Services, SA</p>	<p>Research and Development – The Way Forward</p> <p>Chair: Dr Jack Best Chair, Strategic Research Development Committee, National Health and Medical Research Council, NSW</p> <p>Professor Peter Yellowlees Director, Centre for Online Health, University of QLD</p> <p>Professor Enrico Coiera, Co-Director, Centre for Health Informatics, University of NSW</p> <p>Ms Ann Davies, Chief Executive Officer, IBA Technologies Ltd, Vic</p>

EXPORT OF AUSTRALIAN ONLINE HEALTH SERVICES

4.10 **Exporting Health Information Solutions to the World**

Chair: Mr Mick Bolto, NHIMAC Member and Freehills Project Solutions, WA

Dr John Ainge, Chief Executive Officer, Atmedica Asia Pacific, ACT

Ms Char Weeks, Relationship Development Manager, Health Communication Network, Vic

Ms Yvonne Packbier, Chief Executive Officer, Collaborative Health Informatics Centre, Qld

4.50 **Closing Address from the Chair**

7:00 **Conference Dinner**

Friday 4 August 2000

9.00 Welcome and Opening Remarks from the Chair

Professor Richard Smallwood, Chair, National Health Information Management Advisory Council and Chief Medical Officer, Commonwealth Department of Health and Aged Care, ACT

EMPOWERING CONSUMERS AND COMMUNITIES FOR BETTER HEALTH

9.05 The Future of Health Information – A Social Commentary

Ms Geraldine Doogue, Journalist, Broadcaster and Social Commentator

10.00 E-health for Consumers – Benefits and Risks

Chair: Mr John Rimmer, NHIMAC Member and Acuity Consulting, Vic

Mr Matthew Blackmore, Executive Director, Consumers' Health Forum of Australia, ACT

Mr Martin Fletcher, Director, Quality and Consumer Section, National Health Quality and Priorities Branch, Commonwealth Department of Health and Aged Care, ACT

11.00 Morning Tea

SUPPORTING CLINICAL CARE

11.20 A National Approach to Electronic Health Records

Ms Lynelle Briggs, First Assistant Secretary, Portfolio Strategies Division, Commonwealth Department of Health and Aged Care and Chair, National Electronic Health Records Taskforce, ACT

12.00 Lunch

Clinical Information Systems Terrace 1 and 2	Telehealth Crystal Room	Information for Decision Support Terrace 3
What's New and Innovative? Chair: Dr Tom Stubbs , Chief Information Officer, SA Department of Human Services Dr Kym Bannister , Head, Renal Unit, Royal Adelaide Hospital, SA Ms Dianne Ayres , Manager, Clinical Systems, NSW Health Ms Rachel Stephen-Smith , Consumers' Health Forum, ACT and Professor Michael Kidd , Chair, General Practice Computing Group, NSW Dr David Woodcock , Chief Information Officer, Peter MacCallum Cancer Institute, Vic	Telehealth – Beyond the Think Tank Chair: Dr Michael Walsh , Chair, ANZ Telehealth Committee and Chief Executive Officer, The Alfred Hospital, Vic Dr Ilse Blignault , Telemedicine Manager, Queensland Telemedicine Network, Qld Ms Helen Cooper , Deputy Mayor, Flinders Island Council, Tas Ms Maxine Drake , WA Health Consumers' Council	Enhancing Decision Support Chair: Dr George Cerchez , NHIMAC Member and ADGP and GPCG representative, Tas Mr Craig Patterson , Director, Health Policy Unit, Royal Australasian College of Physicians, NSW Dr Chris Baggoley , Chair, Committee of Presidents of Medical Colleges (immediate past president of ACEM), Vic Dr Ken Harvey , School of Public Health, La Trobe University, Vic

2.30 Afternoon Tea

USING INFORMATION TO BUILD A BETTER HEALTH CARE SYSTEM

Building a Better Evidence Base Terrace 1 and 2	National Administration Data Crystal Room	E-Commerce Terrace 3
Building a Better Evidence Base for Health Care Delivery Professor Richard Smallwood , Chair, National Health Information Management Advisory Council and Chief Medical Officer, Commonwealth Department of Health and Aged Care, ACT Professor Michael Kidd , Chair, General Practice Computing Group, NSW Ms Fiona Tito , Director, Enduring Solutions, ACT Ms Carolyn McNally , Assistant Secretary, Information Design and Delivery Branch, Health Insurance Commission, ACT	Using and Managing National Administrative Data Chair: Dr Richard Madden , Director, Australian Institute of Health and Welfare, ACT Dr James Semmens , Deputy Director, Centre for Health Research Services, University of Western Australia Associate Professor Rosemary Roberts , Director, National Centre for Classification in Health, NSW Dr Chris Kelman , Director, Research and Analysis Section, Department of Health and Aged Care, ACT Dr John Bass , Health Insurance Commission, ACT	Where is E-Commerce Heading in Health? Chair: Dr Paul Twomey , NHIMAC member and immediate past Chief Executive Officer, National Office for the Information Economy, NSW Ms Susan Medlin , Manager, Strategy Management Team, VIC Department of Human Services Dr Stephen Judd , NHIMAC member and Hammond Care Group, NSW Mr Phil Dibben , National Councillor, Pharmacy Guild of Australia, NSW

4.20 Closing Address from the Chair – Next Steps

Speaker presentations

Opening address

*The Hon Dr Michael Wooldridge
Minister for Health and Aged Care
(pre-recorded address)*

I am delighted to have the opportunity to participate in the National *Health Online* Summit. I would have liked to attend in person but it is perhaps entirely appropriate that while you are gathered to discuss *Health Online* you briefly receive transmissions from 'Health Minister Online'.

My 'virtual' presence at the Summit is just one example of the ways that new technology assists us to undertake our daily activities in an age of rapid developments in these technologies.

I have a simple vision for the use of information technology in health which is to harness it to deliver benefits to the individuals and communities that receive health services in Australia. That is, to achieve better health for all Australians wherever they live.

On the one hand, I do not want to stifle innovation in developing solutions to today's information needs. The information technology sector is an extraordinary cocktail of creativity and ingenuity, occasionally fuelled by high-octane stock-market speculation, but providing great potential to develop exciting new ways of working in all fields of endeavour. Arguably, health has been a laggard in harnessing this innovation and we must now make up for lost time.

On the other hand, there are a number of core principles that we cannot compromise on, and these include basic issues like privacy, including individuals exercising a real choice as to who they share personal information with, or whether they do so at all.

When people use health services, they expect that information gained during consultations and treatment will remain confidential. That is, only being divulged within the system on a need-to-know basis. Health matters are obviously extremely personal, so any abuse of the trust placed in a health provider by a consumer can cause great distress or harm.

Australians expect their personal health information to be held securely, to be transferred to a third party only with permission and to be used for research, policy and health management purposes only on an anonymous basis. Consumer trust is an essential element of health care.

These concerns are being addressed as a priority within the *Health Online* strategy, and in the context of the report of the Electronic Health Records Taskforce in particular.

There is no doubt the health industry is on the threshold of great changes as a result of improvements in information management techniques and the use of information

technology. Governments all over the world have recognised that the greater uptake of these new technologies has the power to revolutionise the ways in which health care is delivered and managed by securing improved health outcomes for consumers and improving the quality of care.

Yet we run the risk that, unless we can build on the myriad of activities happening in every State and Territory and across the public and private sectors in a coherent way, we may well end up with substantial duplication and wastage of resources nationally.

We are all familiar with the rail gauge fiasco of last century that resulted in incompatible railway systems being built across Australia. There is the danger that this could happen again with health information. Unless all our different systems can talk to each other, we will simply fail to realise the full potential for health consumers.

It was with this in mind that Australian Health Ministers established the National Health Information Management Advisory Council and subsequently approved the directions document *Health Online: A Health Information Action Plan for Australia*. The Council is playing a pivotal role in advancing health information management issues and I congratulate everyone involved for their work and for convening this Summit.

The Electronic Health Records Taskforce has also been a key driver in examining these important issues and preparing a thorough and well-researched report.

And we have established a presence on the Internet called Health*Insite* as an authoritative source of information on health matters for consumers. It contains information backed by leading national and international health organisations and is well worth a look if you have not already seen it.

You will hear much more about all of these initiatives from the speakers today and tomorrow and I urge everyone to take advantage of the opportunities this Summit presents to share and exchange information and views.

There are a few thoughts I would like to leave you with as you participate in the rest of the sessions at the Summit.

One is that whatever actions we take in the future, it is of paramount importance that the community is fully engaged in the process and that we empower individuals and communities to make informed decisions for themselves.

Secondly, in delivering benefits to health consumers we need to distinguish between the 'rail gauge' issues of ensuring a seamless delivery of basic services and planning for the more innovative solutions that are sure to arise in the future. This is explicitly recognised in the Mission description for the *Health Online* Strategy where it refers to 'the effective and innovative use of health information'. We need to walk before we run on this issue.

We need to develop effective systems to replace the existing paper-based systems of managing personal health information, but we also need to keep an eye on the vast potential for innovative approaches to health information to support healthcare in the future.

This is particularly so in regional, rural and remote areas, where information technology has the potential to make major advances in overcoming isolation and geographical disadvantage via various telehealth initiatives.

Australia is a world leader in the area of telehealth services and we must use this advantage to enable Australians, no matter where they live, to have access to high-quality, real-time interactive health advice, treatment and assistance. And while we are planning for the future, we need to ensure the consumer-based issues of quality, safety and privacy receive top priority.

I believe that collectively, governments, consumer groups, health care providers and other interested parties have made a good start on managing health information to benefit Australians. But there is much more work required to be done and this Summit is an important step in that process.

You have an interesting few days ahead of you with a comprehensive program of distinguished speakers to illuminate these issues and provide a range of challenging perspectives. I look forward to hearing more of the activities of the Summit and wish you an interesting and enjoyable time as you participate in this landmark event.

AN INTERNATIONAL PERSPECTIVE ON HEALTH INFORMATION MANAGEMENT

Health information systems – recent developments in Canada

Dr David Mowat

Director General (A), Centre for Surveillance Coordination, Population and Public Health Branch, Health Canada

Health services in Canada

Provincial jurisdiction

- most health services

Federal jurisdiction

- direct (First Nations, others)
 - regulatory
 - support and leadership
 - funding
- Single-payer insurance, private delivery
 - Canada Health Act:
 - universality
 - comprehensiveness
 - portability
 - public administration
 - accessibility

Some problems

- Poor integration of services, records
- Interoperability problems
- Lacking strong mechanism for collaboration
- Slow adoption of ICT
- Emphasis on inpatient information
- Lack of data models
- Lack of policy framework, e.g. privacy
- Need for better accountability
- Need for more timely, comprehensive data on diseases and determinants
- Need to improve access to care in remote areas
- Poor access to evidence
- Need for trustworthy Canadian information for consumers
- Need for leadership, incentives

Established mechanisms

- Statistics Canada;
- Canadian Institute for Health Information (CIHI);
- Federal/Provincial/Territorial committees; and
- Provincial developments.

Canada Health Infoway

- Empower the general public;
- Strengthen and integrate services;
- Create strategic information resources; and
- Improve privacy protection.

Canadian Health Infostructure

- Canadian Health Network (CHN)
- First Nations Health Information System (FNHIS)
- National Health Surveillance Infostructure (NHSI)
- Office of Health and the Information Highway (OHIH)

Canadian Health Network

- Easy access to health information you can trust from over 500 organizations across Canada.
- Information on health promotion and disease prevention.

MSB mandate and role – who are we?

- 635 communities, half million population.
- Annual budget \$500 million.
- Responsible for the provision of *basic public health services* for all First Nations communities & Inuit peoples.
- Responsible for provision of clinical care in remote nursing stations.

Suite of products

- Client core
- Immunization
- Reportable & chronic disease
- Psychosocial
- Maternal
- Environmental
- Abuse
- Test/exam
- Medication

- Adverse reaction
- Public health education
- Mortality information

Where are we now?

- Primary technology issues have been addressed.
- Major challenges now relate to developing the human skills & capacity to manage the Health Information System (HIS) and integrate with the emerging health infostructure.

Milestones for 2000/2001 and beyond

- Feasibility studies, design, prototype, pilot and implement links to:
 - other MSB information systems; and
 - provincial and territorial health and surveillance systems.
- Data entry & conversion.
- Training, education & transition.
- Development of community, regional and national skills and abilities to:
 - manage and exploit the full potential of the First Nations Health Information System; and
 - to support successful transfer.

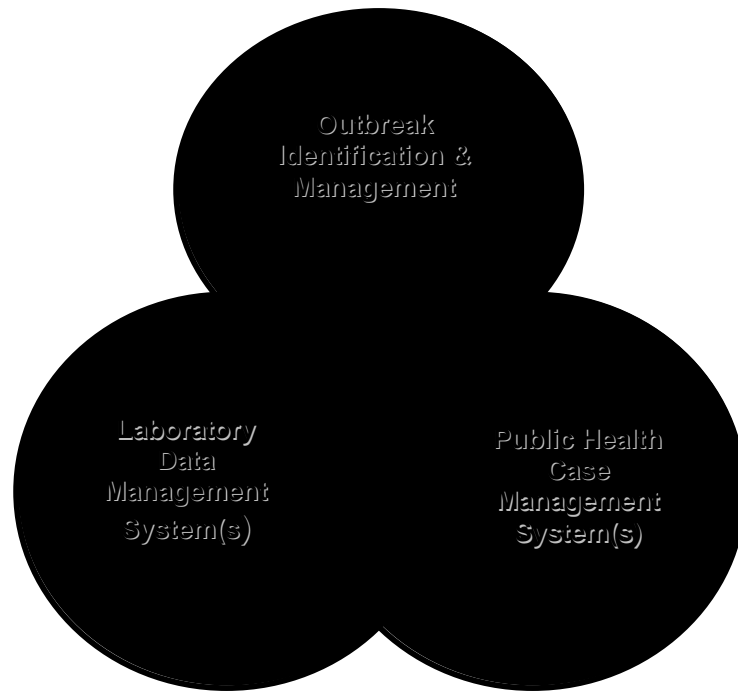
What is the National Health Surveillance Infostructure (NHSI)?

- One of three components of the Canadian Health Infostructure (CHI)
- Series of integrated pilot projects:
 - internet-based;
 - support national health infrastructure; and
 - complement provincial, regional & local activities.
- Employ a common information management approach.

What is the Network for Health Surveillance in Canada?

- A collaborative effort involving Health Canada, provinces/territories, local public health authorities, academics, non-government organizations, Statistics Canada and the Canadian Institute for Health Information.
- An attempt to build up the capacity to undertake surveillance.
- Incorporates and builds upon the National Health Surveillance Infostructure.
- Involves Information and Communication Technology pilots, standards, policy development, knowledge management, skills development.

Canadian Integrated Public Health System (CIPHS)



Spatial Public Health INformation eXchange (SPHINX)

- Business Intelligence Application.
- Partnership with Alberta WellNet, operating in 17 Regional Health Authorities; enhancements being developed.
- In-use with notifiable diseases; vital statistics and cancer to follow.

Global Public Health Intelligence Network (GPHIN)

- Searches newsfeeds/web for news reports of disease outbreaks/hazards.
- Now provides nearly half of information on the World Health Organization's outbreak list.
- Enhancements by September: neural network, translation utility, web spider, discussion forum, ticker.

Product-related Risk Data Network (ProdNet)

- Surveillance of adverse health effects of consumer products.
- Links emergency rooms and poison control centres to Product Safety Bureau, Health Canada.
- Prototype complete, production version in development.
- Formation of consolidated database under way.

Mother-Net

- Surveillance of risks from drugs and other exposures in pregnancy and lactation.
- Will build on the existing work of our partners at MotheRisk, in Toronto and Montreal.
- Increases the quality of bilingual information services to women, clinicians, regulators, and health surveillance users.

Injury surveillance

- Will demonstrate use of ‘circumstances of injury data’.
- Uses component of NACRS (developed by the Canadian Institute for Health Information).
- Collect-analyze-use in programs of prevention.

Architecture

- Data model.
- Standards:
 - nomenclature
 - classification
 - minimum data sets

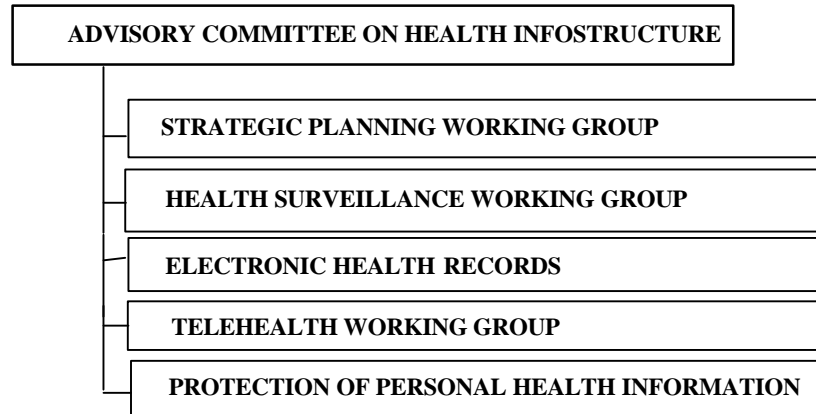
Access

- Electronic access.
- Language.
- Discovery.
- Permission.

Mandate of ACHI

- To advise the Conference of Deputy Ministers on strategies to support the development of a national health infostructure by:
 - identifying emerging health infostructure issues;
 - designing a strategic approach to the development and implementation of health information systems;
 - identifying opportunities *for* inter-provincial and federal/provincial/territorial collaboration, and its promotion; and
 - promoting the sharing of best practices.

ACHI structure



Electronic health records

Why is it important?

- improving care at point of delivery
- information for providers
- accountability
- information for patients
- greater potential for security

What is it?

- not sum of all existing records
- person-centric extract
- physicians, other providers, labs, pharmacies, home care, public health

The EHR – what is it?

- However, whatever the actual form the electronic health record takes, it will make provisions for:
 - a unique personal identifier
 - a unique provider identifier
 - a unique facility identifier
 - some amount of administrative data (including ‘tombstone’ data)
 - some amount of clinical data

Electronic health records – what’s happening in Canada?

- Provincial and Federal governments have begun to allocate significant funding to electronic health record development, for example:
 - HISP; CHIPP; Wellnet; SHIN, etc.

- On a regional basis provinces have begun to plan cross-jurisdictional initiatives to design and build key electronic health record components.
- CIHI is working to develop and maintain the standards necessary for the development of an electronic health record.
- Electronic Health Record Working Group has been formed to provide leadership on the development of an electronic health record.
- It is recognized that the involvement of a wide variety of stakeholders is key to the development of an electronic health record.

Telehealth: key issues

- Interoperability;
- Virtual knowledge centre/best practices;
- Licensure;
- Telecommunications rates;
- Commonalities - evaluation/business case issues; and
- Reimbursement

Funding programs

- Health Infostructure Support Program (HISP)
 - supports efforts to test and assess the use of new information technologies and applications in the health field through pilot projects;
 - Health Canada, health professionals and other stakeholders jointly invested \$22 million; and
 - 36 groundbreaking projects, developed by communities from coast to coast.
- Canada Health Infostructure Partnerships Program (CHIPP)
 - two-year, \$80 million, shared-cost program;
 - supporting the implementation of innovative applications of information and communication technologies to bring better health and health services to Canadians;
 - multi-jurisdictional collaboration; and
 - priorities: electronic health records and telehealth.

Challenges

- Buy-in : public, providers, governments;
- Protecting investment;
- Reverse history of failure of IT projects;
- Standards, Interoperability;
- Consensus building, collaborative approaches;
- Longer-term perspective, shorter term results; and
- Focus on national priorities.

A NATIONAL COLLABORATIVE APPROACH – KEY ACHIEVEMENTS AND FUTURE DIRECTIONS

Advancing national collaboration - key achievements and future directions

Mr Michael Reid

Chief Executive Officer, NSW Health

Thanks to our Chair – Professor Richard Smallwood and my co-speakers Kate Moore and Frank Quinlan in this plenary session on Advancing National Collaboration.

Today I speak wearing two hats, as Director General of NSW Health and as Chair of the National Health Information Management Group. I am also conveying thoughts from David Gates who, as Chair of the ANZ CIOs' Forum and a member of NHIMAC is especially interested in establishing collaboration across the breadth of the Online Strategies.

This presentation will add to the consumer and GP perspectives provided by my co-speakers and will explore how health system organisations will collaborate on key strategies within the *Health Online* agenda.

The fact that the health industry is highly complex and made up of many significant stakeholder groups is nothing new. Each group within the health industry has its own critical business issues to manage but increasingly common themes are emerging at regional, state, national and international levels.

In order to address these issues a range of collaborative forums exist. Within each forum consistent themes emerge:

- Sharing information
- Learning from past experiences
- Planning coordinated approaches
- Working together to move forward

However, in the past many of them have worked in relative isolation. This has been particularly so in the information area before the *Health Online* Strategy which establishes a solid framework, albeit somewhat Commonwealth focussed at present.

Real benefits begin when information flows between as well as within, the groups. The *Health Online* themes developed by the National Health Information Management Advisory Council (NHIMAC) are a worthwhile starting point for further collaboration.

Laying sound foundations

Sound foundations are required to support our rapidly growing information needs. For example, in order to get buy-in from all interested parties it is essential that privacy and security issues are addressed, and that we understand what each piece of information means, where it is stored, how it is transferred and who has access to it.

Access to information should not be limited by location or time.

A robust and secure telecommunications infrastructure is fundamental to achieving this, and along with privacy and security, is a fundamental issue currently holding us back.

We all make use of the health system at some time in our lives although hopefully not too often.

As consumers of health services when we do need to use them, we need to have confidence in them.

As Kate will discuss, consumer confidence can be heightened by supporting consumers through:

- informed choice;
- informed consent; and
- providing practical assistance in accessing their personal health information and relevant general health information.

The key objective of any health system is to deliver appropriate, quality health care.

Particularly relevant to hospitals is the need to capture data at the point of care and deliver quality information to clinicians, along with tools to support on-the-spot clinical decisions.

It is critical that this information is provided at the point of care, at the time of care, irrespective of the care provider, care setting or time of care delivery.

Technology now provides tools to support this. *HealthConnect* has provided a strong trigger for health organisations to achieve this outside the boundary of the hospital and across the full life history.

The task now is to harness technology and provide systems to support clinical care.

The key to improving the health system is:

- understanding the information we already have;
- combining it where it makes sense;
- sharing it where appropriate; and

- leveraging it to learn, to grow and to become increasingly competitive in the global marketplace.

Leveraging basic information can lead to phenomenal results with potential gains in reducing adverse events and better coordination of care.

The clear winners will be the health of Australians and the Australian health system.

So let's see what we can learn by looking at the work programs of two collaborative groups

- the ANZ Chief Information Officers' Forum; and
- the National Health Information Management Group.

First, the Australian and New Zealand Chief Information Officers' Forum. The Forum represents public health system providers in each State and Territory plus the Commonwealth Department of Health & Aged Care, National Office for the Information Economy and the Health Insurance Commission.

Their work plan is based on the *Health Online* themes. A couple of examples are:

- National Collaboration where:
 - the NHIMAC collaborative structure endorsed by NHIMAC was put forward by the Forum; and
 - work is currently beginning on the development of a National Information Architecture which relates the *Health Online* strategies to each State's business objectives, identifies information requirements, technology requirements and governance issues from a State perspective.

In short, this allows State initiatives to be mapped in context and identifies gaps for further action.

It will clearly fill the need expressed by the South Australian Health Minister at the recent conference where it was agreed that State activities need to be mapped and related in a stronger fashion to *Health Online*; and

- Laying Sound Foundations where the Forum:
 - puts forward the State's priorities on Standards to be incorporated in the National Health Information Standards Plan; and
 - is currently developing a national position paper for a National Health Telecommunications Framework in response to a request from the last NHIMAC meeting.

Future directions include a more formal structure and relationship with NHIMAC. This is to be put to the next Australian Health Ministers Advisory Council meeting.

The future focus will be on:

- how States support the *Health Online* Agenda

- mapping that agenda to activities at the Health Organisation Level, finding and addressing the gaps; and
- planning and acting in collaboration on key issues.

And continuing to involve:

- industry (via the Collaborative Health Informatics Centre and through them with other groups such as the Australian Information Industry Association);
- private providers at organisation and individual CIO levels; and
- the General Practice Computing Group will be represented on the Forum from the next meeting.

In contrast, the National Health Information Management Group deals specifically with data related issues around the theme of Laying Sound Foundations. It is responsible for implementing the National Health Information Agreement. To do this it brings together a broad group of stakeholders.

The current NHIMG work program includes:

- maintenance of the National Health Data Dictionary, including extension to include operational and clinical terms;
- the endorsement of specific health Data Sets;
- the development of a National Indigenous Health Information Plan; and
- maintenance of the National Health Information Knowledgebase.

Achieving national collaboration in health is obviously complex and needs focus. NHIMAC has adopted a structure based once again on the themes of *Health Online*. Following consultation NHIMAC selects issues to become Target Areas and by consensus allocates tasks to specific groups.

Putting this into practice results in the following process flow:

- selecting the Target Area and preparing a scoping paper for NHIMAC endorsement;
- selecting and identifying the NHIMAC sponsor and secretariat;
- convening a Task Force;
- developing a proposal for national action;
- reporting on this proposal to NHIMAC/AHMAC and Health Ministers; and
- establishing an implementation plan

Several projects have been or are currently moving through this process. *HealthConnect*, now endorsed by Health Ministers is moving into its detailed implementation planning stage. As Professor Smallwood mentioned, a Taskforce to progress Supply Chain Reform issues has recently been established under NHIMAC.

Likewise the refinement of the National Health Information Standards Plan and formation of the National Health Information Standards Advisory Committee (NHISAC) is just commencing with NHISAC's first meeting scheduled for September.

Telecommunications has just entered this process with the ANZ CIO Forum's development of a proposal for a National Health Telecommunications Framework.

So let's put all of this together by looking at the work of the National Electronic Health Records Taskforce.

HealthConnect started life as an outcome of the Electronic Health Records Task Force. Signed off by Health Ministers last week, HealthConnect will now move forward to developing detailed implementation plans. From a State perspective, I encourage early consultation with the IT Industry and health service providers as part of this process.

It is critical that we collaborate on:

- the impacts on specific focus groups (such as NHIMG and ANZ Telehealth Committee);
- impacts on providers (through the ANZ Chief Information Officers' Forum);
- consumer communication (at Commonwealth and State levels); and
- specific issues such as privacy and security.

Two streams of activity are therefore important - both ongoing collaboration plus reporting to the Implementation Group (yet to be appointed) and NHIMAC.

We will hear more about standards activities this afternoon, but briefly the National Health Information Standards Plan has been endorsed and the National Health Information Standards Advisory Committee has been established.

In parallel with this:

- a Memorandum of Understanding is to be developed between Standards Australia, NHIMG, ANZ CIO Forum and the GP Computing Group;
- the ANZ CIOs' Forum is providing input in relation to State Priorities; and
- involvement of consumers and industry representatives will be discussed at the first meeting.

Once again, specific action supported by ongoing collaboration.

In conclusion, the *Health Online* agenda is broad based and **will only be successful if** we can fully engage:

- States & public health care providers;
- private health care providers;
- the broader community; and
- industry

and if we can call upon existing knowledge sources within a coordinated framework.

In short "collaboration is essential to success".

Advancing national collaboration – a consumer’s view

Ms Kate Moore

Consumer representative, National Health Information Management Advisory Council

Four months ago I broke my right arm. At the time I thought well, it may hurt a bit, and it’ll be a bit inconvenient – but I only have to put up with my arm in plaster for a few weeks and then all will be well.

Instead, I found myself being sucked into a sort of vortex of visits to multiple doctors, tests, x-rays and therapy which seemed to be taking over my life. It was time consuming, expensive and very disempowering. It got to the point where I felt I was single-handedly supporting the entire health care system. It’s an experience I survived by treating as field research for the work I do. So today I want to reflect on how the introduction of e-health might have improved my experience – and those of thousands of other consumers who have the same sort of experience every day.

I’ll concentrate on technology as a tool for managing the information provided by consumers to the health system, and for delivering information to consumers.

Technology can be a very powerful tool for empowering consumers. It can deliver information which will help us manage our own health. It can also use the information generated from our own experiences of disease and health care to improve treatments and services.

There is, I think, a rather dangerous assumption that just bringing in new technology will bring about improvements – but if it’s not done carefully then it will increase inequalities and exacerbate problems which already exist. If technology is to truly empower consumers and communities (one of the key themes in *Health Online* – and one of our biggest challenges) then we need collaboration between the various interests and between the different levels of government. What I am looking for is genuine partnerships where the contribution of each is equally valued.

Last week’s announcement that ministers have agreed to the development of electronic health records was a fine example of what can be achieved through collaboration. The National Electronic Health Records Task Force should be congratulated – they have done a fine job. And we need that sort of collaboration to keep going – because unless we do we will have a system that does not meet the needs of everyone involved – the consumer, the clinicians and other health care workers, researchers and governments – who pay the largest slice of the bill! I fear we will end up with a different and incompatible system of records in each State or Territory, or with different records in different parts of the health system. Collaboration is essential if we are to ensure everyone’s needs are met, that duplication does not occur and that State initiatives such as the health information network in the ACT are a part of the national effort.

I'm really looking forward to having an electronic health record. It would have helped me enormously through my episode of care – and I'm sure it would have helped the doctors and physiotherapists who were providing care. As I get older it would help me even more as my needs become more complex.

I was pleased to see the Minister's emphasis that participation in a scheme of electronic health records is to be voluntary – but I'll bet that providing the system is designed properly, then most consumers will opt to be part of it – because it will give us more control over what happens to us – and it will improve care.

Being able to opt in is, of course, the first step in empowering consumers. A second critical aspect is ensuring that consumers have access to what is on their own record. I'm lucky enough to live in the ACT, which is the only place in Australia where we have had the right of access to our health records.

I'm glad to say that in spite of the dire warnings of the medical profession when this legislation was mooted, the sky hasn't fallen in.

After breaking my arm, and then learning that I may need some strategies to care for my bones as I get older, I find myself needing to make some difficult decisions – and I wanted to look back on my history so that I have a better understanding of the problems I had experienced in the past. So I sought access my past record. I'm happy to say that the providers willingly provided it and it did enable me to make some decisions about future care. It was great to be able to exercise that right, and to be able to access the information I need to make decisions about my own health. In short, it was a simple, but important means of empowering me in a system that is uncoordinated, fragmented and confusing – and that often keeps me in the dark about my own health care.

So as we move to an electronic record, all sorts of things are possible. The record can not only help us to coordinate our care, but it can potentially make all sorts of information about us available for research purposes, which in turn provides better evidence about treatments and about services. And all this will happen only if the consumer consents to its use. Obviously, the more consumers who consent to use of their information for research purposes, the better will be the data available for research – so it's in all of our interests to make sure that there is enough confidence in the system to enable consumers to trust that their information is used properly.

All the research I have seen and done about consumers' attitudes to the use of their own personal health information for research shows that people are, by and large, willing to have their information used for this purpose. But they must be able to trust the system to use the information properly. Recently, I took part in some consultations with consumers about the use of the information held in Health Insurance Commission databases. It was very clear that participants in that process were keen to use that information to improve health care – but they were very wary of what else the government might do with the information. They all raised issues about the Tax Office's apparent misuse of information.

The governance of the Health Information Network for Australia is going to be critical. I suggest that how we structure that and how it operates, and who is involved in it are things we need to take great care with. It needs to be set up as a collaborative effort between governments, consumers and health care providers – and its processes have to be robust and very transparent.

The report of the Electronic Records Taskforce does recognise that consent is a key to participation in the network. The focus groups, which tested out the *Health Online* concept and the research that I did for the Health Insurance Commission showed that the nuts and bolts of how consent is sought are very important – and yet very little work has been done in this area so far. I'd go so far as to say that the health system is not good at seeking consent. One screening service I visit regularly asks me to consent to the procedure and the use of my information for research in the one question. I don't apparently have the option of saying yes to the screening and no to the research. Every time I go, I point out that this is not a good way of gaining consent – but the consent form has not changed. And one doesn't complain too loudly prior to undergoing a procedure involving inserting your breasts into something akin to a trouser press.

The issues in giving consent are not simple – consumers want flexible, layered consent so that we can decide who has access to what information and under what circumstances. We are, by and large, not happy to give a wholesale, blanket consent that lasts forever. On the other hand, we don't want to be continually pestered by researchers wanting us to consent every time they want to use the information.

The Electronic Health Records Task Force has done a splendid job in spelling out the necessity for consumers to control the use of our information. But I think it's now time to take the next step and start spelling out just what consent means and how it can happen. We need to do that before we start designing the technology – so that the technology suits its purpose of empowering consumers, rather than the other way around.

Access to information

For consumers **access to information and to the technology** that can deliver it is becoming increasingly important. Access to the technology is critical because it will be the means through which all sorts of information is conveyed – whether it be our personal health information held on electronic records, or information that is already available on the Internet about the things that can go wrong in our bodies and the things that may or may not cure them.

Five weeks after breaking my arm the plaster came off and I was preparing to resume normal activities when I was diagnosed as having a complication – a potentially nasty condition I had never heard of. The orthopod who diagnosed this condition didn't tell me about it – but he did tell my GP who, fortuitously, I went to see to discuss a different problem. Fortunately, he mentioned it to me as he was showing me out of his door (if I had had an electronic record I would have known about it earlier – and maybe it would

have smartened the specialist up so that he had to tell me and to explain what it was. It would also have informed the other health providers I see about my progress. So it would also have improved my medical care).

So having learned about this diagnosis almost by accident I, of course, went straight to the Internet to find out about this thing I had never heard of. The first thing I looked at told me that 80% of people with this condition are permanently disabled after 18 months. The next thing I looked at talked about chronic pain and permanent disability. And it didn't get any better. I revisited the web several times over the next few weeks and I got very depressed. But I'm lucky – I have a good friend who knows her way around this information – and she firmly told me not to look at it any more – she would go through it and find the good consumer information – which she did. And it was very helpful – I got vital information that helped me to understand the condition, and which helped me to manage it so that I didn't have to consider the very unpleasant other interventions that were on offer. I understood how the physio would help and how much effort I needed to put into getting my arm and hand working again – and why I needed to do that quickly. So for me, access to good information was essential in helping me to get a good outcome.

I'm not alone in having this experience. I've spoken to thousands of consumers over the past few years. They all speak of needing information so as to understand what they are suffering from, and to help them manage and live with their disease.

The net of course is a great source of information – that's why those of us who have access to it, use it. But it can be confusing, it can give us wrong information and it can unnecessarily alarm us. What we need is help to sort through the information. That is why over-reliance on technology, in isolation, can be dangerous, and can exacerbate problems that already exist.

Consumers don't want to have to rely on the net. We would like our health providers to communicate with us and give us as much information as possible, and guide us towards information that is authoritative, reliable, thorough and consistent.

Recently I saw a consumer information database called Healthwise. It was put together by a group of consumers and doctors and health funds in the USA – with some funding from a philanthropic foundation. It is a comprehensive database of thousands of pages of health information for consumers. It's in simple English and well indexed – easy to find your way around. It's exactly the sort of information they need, and I'd love to see something similar in Australia.

It is so good because it was developed collaboratively. It was developed by consumers and doctors and a health insurer working together. What this means is that the doctors know what is in the database – they use it themselves. They know what information the consumer is using. And the consumers know that the information is reliable – it's all based on the best evidence, it's easy to read and it's very thorough. So the consumer and all members of the treatment team have a common information base to work with – and that really works for consumers. It's a great outcome of a collaborative effort – and that

is why collaboration around providing information is essential – starting from the national level.

But consumers need to access technology to be able to use this sort of database. The problem is that less than 50% of households have a home computer. Only 25% of households have home Internet access. Only 44% of our population accessed the Internet at some time in the last 12 months.

So if we are to empower consumers through information it's important that we all collaborate to improve access to the sorts of technology that will really help consumers – particularly those who most need health services and who, because they are sick, are not on incomes that allow them to purchase the technology or the access to the net.

The local consumer group I'm involved with has been lucky enough to have been provided with a computer and Internet access by the ACT government, and we make that available to the consumers in our network. We are now looking for some funding to purchase access to the Cochrane database so that we can also give consumers access to evidence based information. That's one example of how it can be done.

Governments are doing some good things in terms of funding libraries and other community facilities to provide Internet access. But I think we need to be funding not just the infrastructure, but also making sure that training and assistance is available for people using those community facilities.

And if we want people to use them to access health information, then we need to be thinking about how they can access information in some privacy. I don't know how many of you have actually used the computer in a public library – but not surprisingly its quite public. There's a good government program called Networking the Nation which is doing a lot to give small communities computer access in places like the general store – that's really good. But how many of you would be game to go into the general store or the public library and look for some help with your haemorrhoids?

I'm not suggesting for one minute that we shouldn't put computers in places like that – but I'd like to see more collaboration between health departments and the government departments that are installing the computers, as well as collaboration with consumers and communities so that those issues are actually thought through and what is in place can maximise the health benefit from that technology.

So, I think the issues are not just about physical access to computers and Internet – they are also about people being able to use the technology, and to use it in a way that maximises the health benefit – the information has to be appropriate to our needs, and we have to be able to access it in appropriate conditions.

Conclusion

To wind up I'd like to emphasise that use of technology in health has enormous potential. But we have to concentrate on much more than the technology itself. There is a whole lot of other work and effort that is needed to make sure that the technology actually improves health care by empowering consumers – that is the biggest challenge. That work has to be done so that consumers value and trust the technology – and can use it to improve health care. That work must be done by governments, providers and consumers working together – collaboratively.

Advancing national collaboration

Mr Frank Quinlan

National Coordinator, General Practice Computing Group

Abstract

The GPCG provides a successful model for national collaboration in so far as: it is an initiative of the medical profession; it was timely; key stakeholders came together to develop plans and actually collaborated; the Commonwealth committed significant resources to achieve those plans; specific, implementable projects were identified as part of a strategic framework; the framework was implemented independently of government, with its full support; and, industry groups and consumers were directly involved in planning and implementation.

There are also limitations on the model in that: it is difficult, from a Commonwealth level, to develop structures for collaboration with the States; funding cycles are often too short to allow long-term planning; funding cycles are often too short to allow thorough evaluation; the problems being targeted have a high level of complexity; and, many Commonwealth and State initiatives appear, at times, to be occurring in parallel – even isolation.

The future agenda for national collaboration should address a number of issues: change takes time no matter how well planned and implemented, and yet, the rate of change (and demand for rapid change) will continue to increase; the views of the Commonwealth are easily fragmented; the views of the medical profession are easily fragmented; in IM & IT the medical profession and government have had a similar agenda to date but for different reasons, therefore tensions will emerge – principally around monitoring, rationing and clinical independence; in addition, consumers will develop a stronger voice and will articulate limitations and constraints based on privacy that are yet to be felt.

ENHANCING PRIVACY AND CONFIDENTIALITY IN THE WORLD OF E-HEALTH – KEEPING PERSONAL HEALTH INFORMATION SAFE

Enhancing privacy and confidentiality in the world of e-health

*Mr Malcolm Crompton
Federal Privacy Commissioner*

This Session & the session led by Geraldine Doogue tomorrow are the two most important sessions of this Summit

- If the people of Australia don't trust you with their health information and have good reason to do so, the rest of this Summit is academic.

Need to get privacy right for e-health to take off

- [Survey in the US](#) by the California HealthCare Foundation survey:
 - Over 50% of respondents said the shift from paper to electronic record keeping systems makes it more difficult to keep personal medical information private and confidential.
 - 15% of adults said they had done something out of the ordinary to keep their medical information private. This includes:
 - paying out of pocket when insured to avoid disclosure;
 - not seeking care to avoid disclosure to an employer
 - giving inaccurate or incomplete health information on medical history.
- Privacy is daily becoming a more sensitive issue
 - see newspaper clippings.

Starting point for discussion on privacy in the electronic world should be that the community has as much right to privacy in the e-world as elsewhere

- There is potential for the move to e-health systems to do more than this, and actually *improve* the privacy of personal health information (eg by codifying rules for information use and access and by individuals being more involved and better informed about how information can be used and who can access it).
- Very pleased to see the Canadians taking the same approach, as presented earlier in this Summit – *improvement*.

[A Health Information Network for Australia](#) makes very welcome statements about privacy

- ***But*** translating those high level statements into practice will be a big job.
- Realising the potential of an e-health system that improves patient privacy will not come easily or automatically.

Getting privacy right for e-health means carefully listening to the consumer and ensuring consumer representation in the development and implementation of proposals

- Getting privacy right also means people having a right to access their health information. [The Privacy Amendment Bill](#) will provide such a right.

The most significant development from privacy perspective is the introduction of the federal Private Sector Privacy Bill, with its special provisions for the protection of health information

- Provides baseline regulation of all health information wherever held – health clubs, alternative medicine, insurance companies or anywhere else
 - note – this protection based on what it is, not on who holds it.
- Also provides for codes to be developed.
- Update on [House of Representatives Committee report](#)
 - recommended health remains part of the Bill
 - however, the report says legislation should be explicitly recognised as interim and Government should establish process to resolve a consensus view for the health sector in the review of the legislation after 2 years.
 - recommended amendments to individual rights of access to reduce range of reasons for which access to health information can be denied.
- The principles in the Privacy Bill provide a baseline protection for personal information and personal health information.

Within this framework, enforceable codes can cover more specific circumstances

Last week, A *Health Information Network for Australia* indicated that this approach would be taken to the privacy protection of health information in the proposed electronic health record system

- Efforts are already under way to develop a health code.
- Foreshadows that the code will have stricter privacy protection provisions.
- Health providers etc will only be able to join *HealthConnect* if they have subscribed to the code.
- More powerful tools, such as EHR must have corresponding health protection, but within a unified privacy framework.
- Have always supported this approach
 - see [May 1999 Issues paper](#) issued soon after I was appointed.

Unclear how the Victorian Draft Health Records Bill would fit in this framework

- Press reports indicate it is intended to regulate use of health information by health providers as well as health insurance companies, schools, gyms etc.
- Not clear yet how this legislation will interact with the federal Bill.
- Released this week; yet to look at it myself.

The future

- Will the HealthConnect code form the basis of a single health code covering the health system – federal, state & private sectors?
- But such a code unlikely to cover all health information held in the private sector in the near future, including because so much of it is held outside the health system
 - life insurers may in fact have some of the largest holdings in the country
 - will all health providers join HealthConnect?
- Hence Guidelines will be needed to elaborate on how the principles in the Bill apply, to be developed along side of any code development.
 - the Office of the Federal Privacy Commissioner (OFPC) will be developing guidelines on how the national principles apply to personal health information.
 - this will be done in close consultation with stakeholders.
- Guidelines and any code will require a lot work, seeing from others' perspective and even more goodwill.
- The OFPC will be fostering the development of a network of partners interested in developing privacy solutions. Anyone interested in joining up should e-mail/contact the office (privacy@privacy.gov.au).

But to conclude – there must be genuine consumer involvement in the translation of these high level statements into the way health information is used online

- Without it, you will not give the people of Australia good reason to trust you with this information.

Enhancing privacy and confidentiality in the world of e-health

Dr Kerry Phelps

Federal President, Australian Medical Association

Good afternoon ladies and gentlemen - it is a pleasure to be with you today to participate in debate on vital issues surrounding e-health.

In my presentation I will focus on the overwhelming significance of protection of privacy as a precondition for e-health to meet the promises it currently holds out to all those involved in health issues whether it be general practitioners, researchers, managers or policy makers. I propose to demonstrate to you, particularly through reference to international experience, the urgent requirement for development of overarching Federal health information privacy legislation as a critical component of e-health.

I will outline some of the basic principles that the AMA believes should be at the basis of national standards that underpin such legislation. In addition I will highlight the dangers of a piecemeal approach to privacy legislation.

Proposed legislation to be specifically drafted for the Better Medication Management System (BMMS), we believe, reflects this highly risky approach to privacy. The BMMS is a very positive initiative in many ways.

The AMA believes, however, that potentially one of its greatest weaknesses is that in the absence of overarching health information privacy legislation the BMMS, through the development of separate privacy legislation, provides a false sense of security.

I will be emphasising the significance of privacy issues to individual consumers in regard to health information. We may not have Australian data yet on patients' concerns about privacy but they are there, and they are growing. It is important to understand that these issues have no less significance to medical practitioners as they relate to the philosophical and ethical basis of health care provision. The inherent ethical and philosophical basis of health provision is based in the obligations to provide and maintain the confidentiality and privacy of individual health information.

Such obligations are also set down, to varying degrees, in law. Government has an obligation to ensure that health providers are given clear and consistent guidance on their responsibilities under law – particularly in the context of advances in information technology. Most importantly health providers need to be confident that such law is consistent with the ethical and philosophical foundations of their profession.

I am very pleased to see that the Report to Health Ministers by the National Electronic Health Records Taskforce *A Health Information Network for Australia*, that was released on 27 July 2000, generally reflects the views of the AMA in relation to privacy, security and confidentiality of health information. The report states that effectively addressing the

issues of privacy, security and confidentiality, and the development of national standards are two of the most important precursors to implementation of an electronic health information network.

The opportunities offered by advances in information technology to continually improve health outcomes for all Australians are unquestionable and their impact on health, from the individual patient to global issues, is as yet unimaginable. The capacity to realise the opportunities that information technology can bring to health outcomes is necessarily based on access to a vast array of data on aspects of an individual's health and healthcare management – that is, access to what is undoubtedly the most intimate, personal and sensitive of any information maintained about an individual.

Information that is provided through a relationship which is intrinsically based on trust, intimacy and confidentiality – that between medical practitioner and patient. To neglect the significance of this relationship in the development of any electronic health records system is to doom it to failure for where 'consent' of the individual is at the basis of credible data collection, 'confidence and trust' is the basis for 'consent'.

The Government, in partnership with industry, is progressing towards the introduction of the electronic health record. At the same time indications are that its precursor by stealth, the Better Medication Management, in the absence of overarching privacy legislation, will be inadequate in relation to issues protecting the privacy of health information.

Both the Government and the Standing Committee on Legal and Constitutional Affairs had some trouble understanding the grave importance of separate legislation on privacy related to health information.

Consumers, however, increasingly understand that access to data on their individual health history, its current status and, with advances in genetic research, its potential status, may provide the means to: exploit, stigmatise, discriminate and disadvantage an individual in every single aspect of their lives – employment, finances, insurance, housing, education, access to a range of private and public services and travel.

A recent survey showed that more than a third of all Fortune 500 companies in the United States check medical records before they hire or promote and 10% did not inform employees of this practice.

Over two hundred instances of loss of employment, insurance cover or benefits, as a direct result of access to personal genetic information, have been documented in the United States.

63% of the participants in a US 1997 telephone survey of more than 1,000 people reported that they would not take genetic tests for diseases if health insurers or employers could get access to the results. 85% felt that employers should be prohibited from obtaining information about an individual's genetic conditions, risks and pre dispositions.

In discussing the move towards implementation of electronic health records, including the earliest Australian example, Better Medication Management System objectives are consistently stated in general terms of improved delivery and quality of care and improved health outcomes for Australians.

However, the United States has discovered that inadequate, piecemeal approaches to policy and legislation and the absence of overarching Federal privacy legislation, specifically related to health information, has operated as a clear and critical obstacle to the realisation of the benefits to be derived through e-health.

A January 1999 survey by the California Health Care Foundation found that one out of every six people engages in some form of privacy-protective behaviour to shield themselves from the misuse of their health information, including lying to their doctors, providing inaccurate information, doctor hopping to avoid a consolidated medical record and – in the worst cases – avoiding care altogether.

Researchers conducting a multi-year Pennsylvania study designed to understand how to keep women with breast cancer gene mutations healthy reported that nearly one third of the high risk women invited to participate in the study refused because they feared discrimination or a loss of privacy.

In June this year the US House of Representatives and Senate Committee hearings on legislation related to privacy of medical records heard that the absence of enforceable privacy rules was a substantial barrier to improving the quality of care and access to care.

The clear message is that if we want e-health to work there needs to be an overwhelming focus on consumers and providers of health care and what they require as a pre condition of participation, not an afterthought.

So how do we balance the desire to realise the unimagined benefits of information technology in relation to health without compromising the confidence and trust which is the basis for the provision of quality health care?

In terms of electronic health records the critical issue is the capacity to demonstrate that privacy rights of individual consumers and the obligations of providers in this regard, are central to the philosophical, technical and legislative basis of the system. It is in this context that there is a critical necessity for overarching Federal health information privacy legislation based on agreed national standards.

International experience clearly demonstrates that attempts to link a variety of State and Federal legislation, some of which directly relate to health information and some of which do not, is simply not the way to establish an environment of trust and confidence so necessary to make legislation work out there in the real world.

Recent international directions in regard to these issues are characterised by the establishment of consistent overarching standards.

In October 1995 the European Union adopted a “Directive on the Protection of Individuals with regard to the Processing of Personal Data and on the Free Movement of Such Data” which required all member states to bring their national laws into congruence with the Directive.

In February 1997 the Council of Europe adopted a “Recommendation on the Protection of Medical Data”, the principles of which the 39 members (which includes all EU countries) are urged to transpose into their national laws.

In late 1999 the Secretary of the US Department of Health and Human Services proposed regulatory standards related to national medical record privacy which marked the commencement of a regulatory process pursuant to section 264 of the Health Insurance Portability and Accountability Act of 1996.

In a statement by the US Secretary of Health and Human Services in late 1999 she noted that the Administration had called upon Congress to close the gaps in legislation and enact comprehensive national legislation to ensure that all medical records are protected.

Recent experience in other areas of advanced information technology has clearly demonstrated that governments must lead the way. Allowing the market to lead on specific information technology issues in a policy and legislative vacuum places governments in a constant and cost inefficient run to catch up.

Fortunately the pivotal issue of privacy in the area of electronic health records means that existing privacy legislation provides some brake on market advances in this area ensuring access to an increasingly rare commodity – time. Time the Government requires to ensure that comprehensive policies and legislation are established in a carefully considered and fully consultative manner.

The Government may say that the *Privacy Amendment (Private Sector) Bill 2000* meets concerns in relation to health information.

It does not.

This Bill while valuable in its own right is completely inadequate in terms of addressing the immense complexities of privacy protection related to health information, particularly with massive advances on e-health on the horizon. A special health code, if it is agreed to the solution to the inadequacies must be in place before e-health proceeds

The House of Representatives Standing Committee on Legal and Constitutional Affairs Advisory Report stated that “...the arguments of those concerned about the limitations of the Bill have considerable merit and there will be serious problems because of the nature of the health sector.”

Further the "... rules in the legislation, the Committee held, should therefore be explicitly recognised as interim."

So where does this leave us?

On one hand we have privacy legislation at Federal level, and a variety of legislation at State/Territory level that are on the whole inadequate in relation to health information, particularly within the context of new technologies. On the other hand Government and industry are actively progressing the implementation of e-health, specifically the electronic health record, at a rapid pace.

Let me be clear – we want e-health to work. Initiatives such as the Better Medication Management System do have the potential to bring vast improvements in the area of health. We want to realise all the benefits to the health of Australians that e-health can bring. We want to use the technology to bring improved health care and health outcomes to rural and remote communities.

The establishment of national standards that underpin Federal health information privacy legislation is the only way to ensure that these opportunities are not lost. So what are the basic elements that should inform the development of national standards legislation?

While international experience in legislation of this type is varied, it does provide some guidance and consistent themes are evident.

The legislation should establish the minimum of privacy protection at the Federal level for all types of health information and across all sectors to provide national consistency. The legislation should clearly establish boundaries.

With advances in new technologies and new uses the boundaries between health information and other information are blurring and bring with them new issues and concerns. As information technology evolves new uses for the information gathered will also evolve.

The issue of boundaries around use of information is essential in preventing the exploitation of consumer comfort or complacency down the track. An individual's health care information should be used for health purposes, and only those purposes, and any limited exceptions must be clearly defined. It should apply uniformly regardless of the setting in which the health care is provided and apply to all types of information: computer, paper or oral. It should clearly establish limits not only on the use of identifiable information but also the use of de-identified information.

Legislation should establish clear limitations on the use and transfer of de-identified information to prevent data collected for a specific purpose being used for other purposes.

This is essential as the whole issue of consent in relation to exceptions to use of de-identified data is complex and one that must be addressed in terms of 'informed consent'.

In addition, the complex issues of consent in relation to third party use and limitations on the use of the information under legislation by that third party must be addressed. This also goes to issues of coverage of the legislation to organisations not directly related to health care but which have access to health data.

Issues of consumer consent should incorporate the capacity for consumers to know who has accessed their information, when and for what purpose. As a principle, the consumer should be aware of the uses and transfer of information that may not be clear and obvious.

The lack of 'informed' consent creates significant risks to privacy.

There should be an enforceable obligation on the recipient to use the information only in accord with the agreement made with the patient at the time of the authorisation.

The issue is of even greater concern when it is considered in the context of the current climate of increasing corporatisation of medical practice. The fact is, and have no doubts about it, that corporates are about business - and business is about profit.

Corporates are not made up of people who wish to provide the community with a service by investing in health. Corporatisation in the absence of overarching privacy legislation, provides a significant risk to the unauthorised transfer and use of health information for commercial purposes.

A piecemeal approach to legislation cannot ensure that these complex issues are adequately addressed. Legislation must address issues of security and the obligation of record holders to ensure that information is held and transferred to other parties, within the legislation, in a manner which protects the information from being used in a manner contrary to the basis of provision.

Security also relates to the basic principle that the best security is to limit access to 'need to know' for specific purposes.

Consideration may also be given to the development of guidelines for assessing security capabilities of specific healthcare information technology under this legislation.

Lewis Lorton of the US Forum on Privacy and Security in Healthcare notes that in relation to motor vehicles, government and industry have developed a set of standards of structure and safety to encompass the technology that we can't see, can't control and don't necessarily understand.

That such a system does not exist for evaluating the security of the information technology portion of health care information technology systems is a major cause for concern in relation to privacy.

The legislation should be enforceable and establish real sanctions to provide consumers the confidence that the legislation will be applied.

In summary the legislation should establish a basic national standard necessary to protect the rights of patients and define the responsibilities for record keepers. It should authorise sharing of health information for health care treatment and should prohibit use of that information for most other purposes. Legislation should provide consumers with specific rights to know how their information will be used and to know who has used their medical information

I would like to turn now to the Better Medication Management System (BMMS) which is proposed to be available across Australia from July 2001.

The BMMS is an electronic system of keeping an individual's medication records, particularly records of prescription medicines, and has the potential to provide considerable benefits to consumers and providers.

Recalling the issues I have raised earlier, I would like to outline some of the real concerns that the AMA has about this proposal, particularly in relation to basic principles which should apply to protect the privacy and security of individual patients' health information.

Firstly we believe the extremely short time-line allocated to consultation with stakeholders and a period of only 8 weeks to draft specific legislation related to the BMMS is incompatible with the complexities involved in ensuring that consumer privacy rights are central and that consent and access issues are adequately addressed.

As the Electronic Health Record Task Force report states, unless the Government gets the privacy issues right, consumers and providers simply would not use it.

The BMMS privacy sub-group is developing Principles to Guide the Legislation on the operation of the BMMS.

While the principles provide very broad indications on limitations of use of data by those who have access (prescriber and pharmacists), it so far appears to place no limitations on the use of aggregated, de-identified data and proposes that such data should be more widely available for the purposes of performance assessment, and for research and planning relating to the health system.

In our view this represents a somewhat open-ended approach and is inconsistent with the need to establish strict boundaries around the use and re-disclosure of the information.

While the principles indicate that the patient will be fully informed about the BMMS this does not extend far enough to ensure the issue of 'informed consent', surrounding use of data, including de-identified data and use for other purposes, is adequately addressed.

The issue of 'informed consent' must be considered in the context that the uses of data beyond that for which it is collected are unlikely to be obvious to the consumer, in particular. Further, components of the principles which allow further use of data collected through the BMMS indicate that clearly defined and bounded objectives and purposes for the BMMS and the data collected have not been established.

The fact is that technology is evolving and as it does, so will the uses for the data collected within any electronic system. No legislation should provide an open-ended approach to the use of data. A basic principle for security of information relates to limitations on access and disclosure.

The BMMS, however, broadens access and disclosure beyond that which we believe is necessary to achieve the objectives of the scheme. It proposes to provide access to the medication record beyond prescribers to pharmacists – in our view this provides a critical level of unnecessary access and disclosure until we have sorted out the privacy issues like ownership of data and patient permission.

We consider the additional and unwarranted access to represent a serious impediment to security and privacy of individual medication records.

In terms of the technical options being proposed by BMMS they relate to a distributive and a centralised system.

While the technical pros and cons of each of these systems have been put to the working group, the technical systems have not been tested against non-technical issues related to privacy and confidentiality issues.

The technical analysis must take into consideration the array of complex issues related to access and protection of privacy.

The BMMS for example proposes that clear individual identifiers be attached to data, that is a Medicare number, and while this in itself provides cause for considerable concern, the linking of such data into a centralised system may not preclude broader use of data and the introduction and testing of a broader system of electronic health records.

The BMMS was in the Federal Budget, Medicare numbers on prescriptions were in the budget now with out any discussion the two are being linked by stealth with the Medicare number used as a unique patient identifier for the BMMS with absolutely no debate around the UPI.

Dr William Lowrance, in a 1996 study on Privacy and Health Research for the US Department of Health and Human Services, states that while from a privacy protection perspective, there is a very wide distinction between personally identified data and truly anonymous data, in practice the demarcation between these extremes is not sharp.

In this context a centralised system poses the greatest risks to consumer privacy.

The proposed BMMS breaks the first rule in the context of privacy related to electronic health records – that of ensuring consumer and provider confidence through a demonstrated commitment to privacy.

As I have said the BMMS has the potential to bring great improvements in medication management. What it needs to make it work is comprehensive overarching legislation which addresses the complexities, particularly the legal, related to access and to the use of electronic health system data.

The AMA believes this may represent a serious underestimation of public and professional concern over privacy issues – although we are pleased to see that the Electronic Health Records Task Force report gives the issues of privacy, confidentiality and security very strong emphasis.

What we are saying today in relation to BMMS echoes views of the Task Force – get the building blocks, the non-technical building blocks, right or it won't work.

In conclusion I would like to emphasise the AMA's commitment to working with government to improve health outcomes and health delivery through new advances in information technology - technology that is developing at an incredible pace and bringing with it rapid advances in health research.

I have given you a number of examples from the United States that illustrate the risks associated with compromises on individual privacy. Many people will be thinking – yes but that is the United States and Australia is a very different place.

Well I say think again.

Australian consumer focus group patients with long-term diseases advised that they tended to get drugs from pharmacies where they were not generally known. This was especially the case for participants with diseases such as HIV, who felt that they were at high risk of losing their jobs or insurance if their condition became known.

Health is not an area where advances in technology can be simply superimposed. The real limitations of e-health relate to the non-technical elements: the underlying philosophy and ethics of the health profession and the complexities of the human relationships that make it work.

The community, medical and broader health profession, and Government can and must find solutions that will enable the promise of e-health to become a reality.

These solutions lie in protecting the rights of individuals to privacy.

To echo sentiments expressed by the US Secretary of Health and Human Services last year "...the need for Federal protection is not theoretical; it is real and it is urgent".

Enhancing public confidence in an e-health world

Ms Meredith Carter

Executive Director, Health Issues Centre

What is privacy?

- Medical secrecy is central to the trustworthiness of the healthcare system, not only in the private interest of the person. Trust is a fundamental ethical value in itself.

WHO European Group on Ethics in Science and New Technologies (EGE) Opinion No.13, July 1999

Can technology assure privacy?

- Careless corridor conversation by a young doctor led to the disclosure of sensitive information, not previously disclosed to a patient's partner, distressing the partner.
- Staff of public hospitals whose pathology test results had been sent to their employers rather than to their own doctors.

Qld Health Rights Commission Annual Report 1994/95

Human error remains a concern

- A database is as good as the people who put it (the data) in. So when they make a mistake with, for example, your blood group, that can kill you as well as save you.

National Consumer Council, Consumer Privacy in the Information Age, 1999 (UK)

People feel general unease.... about surveillance

- Approximately 5% of population use 70% of health resources
- Linked records may help them use system better eg child immunisation reminders...
- And help the system to penalise them if they don't

People feel general unease.... about commercial interests

- About the sale of their personal information for someone else's profit
- About private contractors handling sensitive information for public services
- About IT systems financed through public-private partnerships

National Consumer Council, Consumer Privacy in the Information Age, 1999 (UK)

People feel general unease....about a lack of control

- People of all ages show willingness to embrace the information age.
- Some can see real benefits. Others are more reluctant, feeling they have little choice.
- People are more willing to participate if they feel they have a measure of control over what happens to their data and can see the relevance of requests for it.

National Consumer Council, Consumer Privacy in the Information Age, 1999 (UK)

People feel general unease...about 'expertness'

- The public has generally had little say over how health services are provided and even less over how the system is organised and funded.
- New ground rules are needed to enable people to participate in setting the agenda and holding the system accountable.

Canada Health Infoway Paths to Better Health, 1999

A strong privacy framework

- Opt in not opt out
- Right of review against decisions based on automated processes
- Publish contracts between public-private agencies
- Informed consent should be clearly defined
- The health sector should be defined
- Proactive monitoring

Secondary uses

- Clear guidance about balancing the public interest in consent versus research
- Prohibit secondary use for commercial purposes
- Clarify secondary use of anonymised/statistical data, taking into account the range of potential identifiability of such information

Redress

- Ensure consumers aware of complaints processes
- Monitoring to ensure compliance with security, consumer requests and responsiveness to complaints
- Full range of remedies including compensation, injunctions and criminal sanctions in appropriate circumstances.

Empowering consumers

- Public confidence in an e-health world also depends on consumer and community ownership of the potential benefits
- The capacity for consumers to participate in the policy debates must be strengthened
- This means the agenda must move beyond a role in which consumers will be the passive recipients of benefits realised by experts.

Aboriginal Health Infostructure

- Resources dedicated for capacity development and training to support aboriginal participation
- First Nation and Inuit Population health info data collection research and analysis to be within a process validated and supported by First Nation and Inuit peoples.

Canada Health Infoway, Paths to Better Health, 1999

Beyond websites

- Consumer organisations have a large role to play helping consumers access information and services...this should be recognised
- People want info to participate as citizens on hospital boards and NHMRC committees
- Organisations like CHF should be resourced to produce evaluations of IT initiatives for the general public.

Canada Health Infoway, 1999

From security to trust

- A broad strategic framework for achieving public confidence in an e-health world goes beyond privacy legislation
- A focus on cultivating a relationship of trust
- And an active role for consumers as citizens
- Key components: transparency, legal protection and public participation.

The Privacy Amendment (Private Sector) Bill 2000

Ms Helen Daniels

Assistant Secretary, Federal Attorney-General's Department

Good afternoon and thank you for inviting me to participate in 'Laying sound foundations' and having the opportunity to discuss the *Privacy Amendment (Private Sector) Bill 2000* with you.

In the time that I have available today, I would like to do four things:

- give you a very brief overview of the Bill;
- take you through some key definitions;
- discuss the major provisions in the Bill that deal with health information; and
- identify some of the issues that we will be dealing with in the near future in applying the privacy standards in the Bill to the field of electronic health records.

Overview

The *Privacy Amendment (Private Sector) Bill 2000* was introduced into Parliament by the Attorney-General on 12 April 2000. The Bill will amend the Commonwealth *Privacy Act 1988* which currently regulates the Commonwealth and ACT public sectors, and private sector organisations that handle tax file numbers and credit information. The Bill will, for the first time, extend general privacy protection to personal information held by private sector organisations, including those in the private health sector.

This is not, of course, going to happen overnight. The Bill is expressed to commence twelve months after receiving Royal Assent. Therefore, there will be time for businesses and other organisations to come to terms with the requirements of the legislation before it comes into operation.

The Government has long recognised the particular sensitivities that exists in relation to health information. Indeed, health information is classed in the Bill as 'sensitive information' which is subject to a higher level of privacy protection than other personal information.

Creating a workable privacy scheme in the health context, therefore, required consideration of many issues and interests. The Government was committed to achieving the right balance between the protection of individual privacy and competing social interests such as the need to facilitate epidemiological research.

The Bill was developed in consultation with many sectors of the community, including many organisations represented here today. The Government is of the view that it does, as a result, strike an appropriate balance.

One of the core features of the way the Bill deals with health information is that it acknowledges that the health profession already has a strong respect for the confidentiality of health information and maintains sound privacy practices in that regard. The Bill is not about interfering with those professional values. Rather, it is about ensuring that consistent baseline standards for privacy protection (which involves a good deal more than just confidentiality) are observed.

National Privacy Principles

The core of the Bill comprises ten National Privacy Principles. These principles (which we often refer to as NPPs) are based on the *National Principles for the Fair Handling of Personal Information* which were developed by the Privacy Commissioner following extensive consultation with business and consumers.

The Privacy Commissioner's principles have been revised to accommodate legislative language and, most importantly for today's purposes, were modified in relation to their application to health information.

The health modifications are based on the Privacy Commissioner's recommendations to Government, following further consultation with health stakeholders. I will take you through the general framework of the health provisions a little later.

The NPPs provide a framework for the protection of personal information. Private sector organisations will be bound by them, unless they are a party to a privacy code that has been approved by the Privacy Commissioner. It is important to point out that such a code will only be approved by the Privacy Commissioner if it provides at least the same standard of privacy protection as the NPPs.

Definitions

At this point it would be useful to go through a number of the definitions in the Bill to provide a better indication of to whom the Bill is intended to apply and what constitutes health information.

Organisation

The most fundamental definition is the definition of 'organisation'. This is important because the Bill is set up so as to apply to the acts and practices of organisations.

'Organisation' means:

- an individual;
- a body corporate;
- a partnership;
- any other unincorporated association; or
- a trust

that is not a small business operator, a registered political party, an agency, a State or Territory authority or a prescribed instrumentality of a State or Territory.

As you can see from that definition, the application of the Bill is very broad.

I should just say something about the organisations that are excluded from the Bill by virtue of the definition. Small business operators are subject to a special exemption. However, the exemption does not extend to small businesses that provide a health service and hold health information. Registered political parties are excluded from the ambit of the Bill so as not to interfere with the free flow of information to and from our political representatives. An agency is a Commonwealth government agency - these are covered by the existing provisions of the *Privacy Act 1988*. And State and Territory authorities and prescribed instrumentalities are excluded as the Bill is about privacy in the private sector and not about regulating the activities of State and Territory Governments.

Health information

The next definition we should discuss is that of 'health information'.

'Health information' means:

- information or an opinion about
 - the health or disability (at any time) of an individual;
 - an individual's expressed wishes about the future provision of health services to him or her; or
 - a health service provided, or to be provided to an individual; or
- other personal information collected to provide or in providing a health service; or
- other personal information about an individual collected in connection with the donation of his or her body parts, organs or body substances.

What is clear from this definition is that it covers the full range of information concerning an individual's health.

Health service

Just as important as the definition of health information is the definition of 'health service'.

'Health service' means:

- an activity performed in relation to an individual that is intended or claimed (expressly or otherwise) by the individual or the person performing it.

- to assess, record, maintain or improve the individual's health;
 - to diagnose the individual's illness or disability; or
 - to treat the individual's illness or disability or suspected illness or disability; or
- the dispensing on prescription of a drug or medicinal preparation by a pharmacist.

This definition covers traditional health services provided by medical practitioners or pharmacists, but also extends into non-traditional areas such as natural therapies and even possibly fitness assessments at a gymnasium. In addition, services that may be performed by a medical practitioner but which are not related to the individual's physical health, such as some elective cosmetic surgery, are covered by the definition.

You might ask why the definition was drafted so broadly as to include a fitness instructor taking your pulse at the local gym. The answer to this, of course, is in the information collected in the course of providing the service. The information collected during an initial consultation with a GP, a natural therapist or a fitness instructor is all likely to relate to an individual's health and be highly sensitive. In that context, and given the intention of the Bill, the definition is an appropriate description of what can constitute a 'health service'.

Specific health provisions

At this point, it is probably appropriate to turn to some of the specific health related provisions in the Bill. This will involve looking primarily at NPPs 2, 6 and 10.

NPP 2

National Privacy Principle 2 deals with the use and disclosure of personal information. In a general sense, it restricts the use or disclosure of personal information for purposes other than the primary purpose of collection unless one of a range of exemptions applies.

These exemptions include that the use or disclosure was done with the consent of the individual or to lessen or prevent a serious and imminent threat to an individual's life, health or safety.

Two health specific provisions are NPP 2.1(d) which deals with use or disclosure of health information in research and NPP 2.4 which deals with disclosure of health information to carers and family members in certain circumstances.

NPP 2.1(d) facilitates the use, in some circumstances, of health information for research or the compilation of statistics relevant to public health or safety.

Those circumstances are where:

- it is impracticable to seek the individual's consent;

- the use or disclosure is in accordance with guidelines approved by the Privacy Commissioner under section 95A; and
- in the case of disclosure, the organisation reasonably believes that the recipient will not disclose the information.

Two things should be observed about this provision.

First, it is only facilitative, it does not compel any use or disclosure of personal information. And second, it has no operation unless and until the Privacy Commissioner approves guidelines under section 95A of the Bill. Section 95A guidelines are issued by the National Health and Medical Research Council or a prescribed authority and may be approved by the Privacy Commissioner if he or she considers it in the public interest to do so.

NPP 2.4 allows for the disclosure of health information about an individual to a person who is responsible for that individual, such as a family member or partner where:

- the individual cannot consent (physically or legally) to the disclosure; and
- the disclosure is necessary to provide proper care to the individual or for compassionate reasons.

However, such a disclosure cannot be contrary to any wish expressed by the individual prior to becoming incapable of consenting.

The legal capacity to consent raises some very difficult issues in relation to minors. The Bill, however, does not seek to change the way health professionals deal with those issues. Rather, NPP 2.4 merely facilitates the continued assessments by health professionals of the capacity of minors to consent. It is not envisaged that the assessment of ‘*Gillick*’ competence will be affected at all by the Bill.

This point extends more generally to NPP 2.4. It is, in effect, simply a codification of current practice.

NPP 6

National Privacy Principle 6.1 provides that an organisation that holds personal information about an individual must provide the individual, on request, with access to that information unless one of a range of specific exemptions applies.

This means that, for the first time outside of the ACT, health consumers will have an enforceable right to access medical records held about them by private medical practitioners.

The extent of such access will be addressed in guidelines to be issued by the Privacy Commissioner after consultation with the private health sector. It is envisaged that a graduated form of access could be arranged so that doctors could, in the first instance,

discuss the contents of the patient's file with them, rather than simply providing them with the whole file to read. However, should a patient wish to exercise his or her right of access, complete access to the file should be given.

As I have mentioned, though, there are a number of exceptions to the right of access. NPP 6.1(b), for example, provides that in the case of health information, access may be denied where granting it would pose a serious threat to the life or health of any individual. This is designed to accommodate the idea of therapeutic privilege. That is, if a doctor believes that revealing information about an individual's medical record to that individual would cause them to be a danger to their own or someone else's life or health, access to the record can be lawfully denied.

Other exceptions to the right of access include situations where the denial of access is required or authorised by or under law; providing access would prejudice an investigation of possible unlawful activity; and where the request for access is frivolous or vexatious.

Clearly some of these terms would benefit from further explanation in the health context. No doubt many of you will be encouraged to participate in the Privacy Commissioner's consultations for the issue of guidelines in this area.

NPP 10

National Privacy Principle 10 deals specifically with the collection sensitive information which, as I mentioned earlier, includes health information.

NPP 10 provides that an organisation must not collect sensitive information about an individual except in certain circumstances including, of course, where the individual has consented to the collection.

NPP 10.2 provides that an organisation may collect health information about an individual if:

- the information is necessary to provide a health service to the individual; and
- the information is collected:

- as required by law; or
- in accordance with rules established by competent health or medical bodies

Clearly, it would be inappropriate for the Bill to interfere with the collection of health information to be used in the provision of health services to individuals.

This provision really just confirms that the collection of information about a patient in some circumstances without that patient's consent (such as emergency situations) is not to be regarded as unlawful provided normal legal and ethical requirements are met.

NPP 10.3 provides that an organisation may collect health information if the collection is necessary for:

- research relevant to public health or public safety;
- the compilation or analysis of statistics relevant to public health or public safety;
- the management, funding or monitoring of a health service; and
- that purpose cannot be served by the collection of de-identified information; and
- it is impracticable for the organisation to seek the individual's consent; and
- the information is collected as required by law, in accordance with rules established by competent health or medical bodies, or in accordance with guidelines approved by the Privacy Commissioner under section 95A.

The circumstances in which health information may be collected, therefore, are very limited.

It should also be observed, particularly in relation to NPP 10.3, that the provisions are facilitative and do not compel the disclosure of health information. Rather, all the provisions do is to clarify that in certain circumstances it is not unlawful to seek to collect health information.

These provisions have been the subject of ill-informed criticism. However, the Government is confident that it has achieved the correct balance between the need to protect privacy and facilitate medical research for the benefit of the community as a whole.

Electronic health records

So how does all this fit with the idea of electronic health records?

The initial answer to that question is that the Bill is designed to be technology neutral. The means by which personal information is collected, used or disclosed is irrelevant to the basic privacy principles that apply to it.

The Bill will represent baseline privacy standards for the use of electronic records in the private sector. We anticipate that the flexibility built into the Bill will allow it to serve in that role regardless of the final shape of the electronic records environment.

The Bill is the beginning of the protection of Australian's health information.

Federal Government initiatives in the health area such as *HealthConnect* obviously involve privacy issues. The Government will ensure that privacy protection is part of the framework for any of its initiatives. Both the Department and the Office of the Federal Privacy Commissioner will be closely involved in developing the privacy framework with colleagues from the Department of Health and Aged Care and other stakeholders, many of whom are present today.

In conclusion, the Federal Government's privacy Bill is a good starting point for health privacy standards. The Government hopes that the health sector will use the flexibility in the Bill to develop a code or codes to protect this sensitive information.

HEALTH INFORMATION STANDARDS – WHERE TO FROM HERE?

Setting national health information standards

Mr Philip Hagan

Chair, National Health Information Standards Advisory Committee

Abstract

Australia has made an important move towards maximising the potential of information technology in the health sector with the establishment of the National Health Information Standards Advisory Committee (NHISAC) – a sub-committee of the National Health Information Management Advisory Council. The Committee will play a key role in advising Australian Health Ministers on priorities for national health information and communication technology standards.

The way forward begins with acknowledging that, without agreed national standards, health information will break down into smaller networks – isolating some jurisdictions, individual organisations such as hospitals, or even individual health providers including general practitioners. Widely accepted and implemented standards are critical to underpin information activities in the health sector, including electronic business transactions (e-commerce), the development of a national approach to electronic health records and exchange of information between different parts of the health sector.

The Commonwealth Government, in *Health Online: A Health Information Action Plan for Australia*, identified the development of national standards for health information management and information technology as a high priority. Crucial to the work of the Advisory Committee will be the *National Health Information Standards Plan for Australia*. The Plan will be a collaborative initiative that will set the framework for the future growth and adoption of interoperable electronic health products and systems. For the first time, Australia will have a mechanism for advancing an agreed national position and a detailed plan for putting standards in place.

In this presentation, Phil Hagan, Chair of NHISAC will outline:

- the importance of national standards to the Australian health sector;
- the roles and responsibilities of NHISAC;
- the aim of the *National Health Information Standards Plan for Australia*; and
- a vision for the future.

National health information standards

Mr Peter Williams

Chair, IT/14 and

Director, Information Management and Clinical Systems, NSW Health

Abstract

The presentation will report on current initiatives being undertaken at the national level by IT/14 and its associated working groups and at the international level by ISO TC 215 and other international groups (eg HL7) in which Australia is participating. This will be followed by discussion about the impact on priorities of national strategies proposed in *Heath Online* and *HealthConnect*.

Health information standards – where to from here?

Dr Oliver Frank

Department of Human Services, Victoria

Abstract

For years, general practitioners, software developers and researchers have called for a standard system for the coding of clinical data in Australian general practice, to facilitate communication between health providers, the development of better software for general practice and research in and about general practice. In 1999, the General Practice Computing Group established a 'Coding Jury' to examine available coding systems and to nominate the preferred system for Australian general practice. The Jury's report is expected to be released before the National *Health Online* Summit, and will be discussed.

Health information standards – where to from here?

Ms Debra O'Connor

Consumers' Health Forum of Australia

Abstract

Health information standards should represent the starting point in the formulation of a comprehensive framework for an information system that primarily aims to improve access to better health and continuity of care for consumers. Such a framework needs to be transparent, readily understandable to consumers and clearly complemented or underpinned by legislative and policy objectives. The standards process is complex and the discourse technical and arcane to the non-initiated. Most consumers would expect that privacy and security standards reflect the highest order possible rather than a minimum set. However, the processes may need to be further demystified for consumers to more fully understand the parameters of these standards.

A general concern for consumers, however, is the need for standards implementation to be monitored and for some public accreditation or recognition that standards are being adopted. A further issue is that standards enable consumer input into their own health information collection and management.

Specific issues include the need to ensure that access to consumer information is closely scrutinised and differentiated according to consumer consent processes. That is, control and consent rests with the consumer and access to *all* consumer information by a provider is not implied by consent in a particular instance. A second specific issue is to ensure that the physical features of the systems facilitate access to their information by consumers. For example, access rights for people with sight or language difficulties or no computer skills will need to be catered for.

Standards development to date has largely represented an ongoing conversation between providers, technocrats, bureaucrats and academics; greater efforts in decoding this conversation for consumers would give them a better opportunity to join in and to ensure that their interests are heard.

Health information standards – where to from here?

Dr Ric Marshall and Mr Neil Powers

Department of Human Services, Victoria

This paper is presented from the perspective of the National Health Information Management Group (NHIMG), which is a working group of the Australian Health Ministers' Advisory Council (AHMAC). AHMAC comprises the heads of the health authorities of each State and Territory and the Commonwealth, all of which are signatories to the National Health Information Agreement together with the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS) and the Health Insurance Commission (HIC). The role of the NHIMG is to manage this Agreement, the objective of which is to establish a framework through which governments can work cooperatively within a national perspective to improve, maintain and share national health information.

The aims of the Agreement are to:

- ensure that the collection, compilation and interpretation of nationally relevant health information is appropriate and carried out efficiently,
- provide a structure and consultative mechanism to ensure that health information and statistics available nationally are accurate, reliable and timely, and
- improve access to uniform health information by community groups, health and community services professionals and government and non-government organisations.

This requires the development of agreed definitions, standards and rules for collecting information and guidelines to coordinate access to and interpretation and publication of information. In developing these standards the NHIMG has become a major influence in developing a coordinated approach to national health statistics and information. It has established formal links with other groups involved in national health information including:

- the National Health Information Management Advisory Council (NHIMAC);
- the National Community Services Information Management Group (NCSIMG);
- the IT14 Health Informatics Committee of Standards Australia; and
- the Australia and New Zealand Chief Information Officers' (CIO) Forum

through mechanisms which include cross-membership, exchange of minutes and joint approaches to some issues such as the development of a national codeset for community based health services.

The NHIMG has recently published Version 8 of the National Health Data Dictionary which contains definitions of about 245 data elements described according to a standard set of rules adopted by the International Standards Organisation and which is now accepted as the authoritative source of national data definitions. Another recent achievement is the Aboriginal and Torres Strait Islander Health Information Plan (*This time let's make it happen*) which recognised that indigenous health was of the highest

priority and that information about it was inadequate and set out a national indigenous health information plan.

From this perspective, and as suggested by the structure of this Summit, the issues around developing standards for health information can be represented from three main interest areas based on the **purpose** that the information is to be used for.

The first purpose is to keep a record of the **health history of a patient** including what has been done to the patient by healthcare providers (clinicians) in order to enable monitoring of the person's individual health status and progress in terms of deterioration or healing of a particular disease. This relates to the individual patient record and is often seen as the primary area of health information.

The second purpose is to **monitor the effectiveness** of the work that is being done by the healthcare service. This includes evaluating which treatments are working and which are not, which providers are providing safe and high quality services and which are not, which groups of people in the community are receiving appropriate and efficient services and which are not. This enables identification of gaps so that services can be provided at a more uniform level. This relates to health service monitoring, evaluation and management and is an essential component of requiring clinicians, managers, administrators and ministers to take responsibility for providing the best healthcare to the community.

The third purpose or use of information is broadly called **health research**. This overlaps to a large extent with the second purpose. However, it has a broader focus on:

- the health status of the population;
- the contributing causes of particular diseases and how they can be prevented or managed; and
- what treatments might work best to cure or prevent the health problems of interest.

Standards are required for all three purposes for which health information can be used. Moreover, a further degree of complexity is added by the fact that health information management standards (like similar standards for information management in other industries) have traditionally focused on two main areas of information management, namely:

- content and analysis (health information or data management); and
- collection, storage and access (information systems development).

The first type of information management standard addresses the questions:

- What is to be collected and stored, in what form and for whose use?
- What are the business rules for recording, providing access to and transmitting records and data?

The second type of standard relates to the media and formats by which records and data are recorded and coded, stored, transmitted and maintained. While this has traditionally

related to the management of paper records and summaries derived from them, it now more properly relates mostly to the operating standards of the IT systems used to manage and access health information.

The stakeholders for each type of standard are summarised in Table 1. Under current arrangements the stakeholders for the first type of standard (in the left-hand column) are represented by the NHIMG and its sub-committees while the stakeholders for the second type (in the right hand column) are represented by IT14.

Table 1. People interested in health in information and requiring particular standards

	WHAT IS RECORDED (NHIMG) How Why For whom	SYSTEM (IT14) Media and formats Storage Transmission
MEDICAL RECORD Health history of a patient	CLINICIANS PATIENTS/ADVOCATES HEALTH INFORMATION MANAGERS	PRACTICE MANAGERS IT SYSTEM DEVELOPERS
MANAGEMENT DATA Monitor the effectiveness, quality-safety of care.	PROVIDERS FUNDERS/PURCHASERS PLANNERS EVALUATORS	DATABASE ADMINISTRATORS INFORMATION ARCHITECTS
RESEARCH ACCESS Treatment best practice, Epidemiology,	EPIDEMIOLOGISTS STATISTICIANS BEST PRACTICE RESEARCHERS	QUERYING TOOL DEVELOPERS

There is of course a great deal of overlap and interaction between the two types of standard shown in the two columns of Table 1. However, the first type of standard is mainly driven by clinical and policy requirements and relates very intimately with policy decisions about the delivery of health services and the reporting requirements of those who use and pay for the services. The second type relates mainly to the type of platform (in the broadest sense of that term) used to record, store, transmit and make available health information.

The result is a matrix of six groups of issues with different stakeholders. Health information standards are required to manage each group of issues and the standards need to be coordinated to manage the resulting health information system as a whole.

1. The clinical record

Information management standards are required to manage such issues as:

- the clinical content of the record, including common terminology, data item definitions, coding, minimum patient data and messaging (eg. HL7);

- privacy issues based on the principle of informed consent for access which may be once only, general or limited by time or categories of content;
- the need for a clear policy on the retention or disposal of records;
- patients' rights of access to records relating to their own health; and
- the review or audit of practice by patient advocates and health information managers.

These need to be supported by system standards relating to:

- system security and access architecture;
- messaging standards;
- networking and communications standards;
- patient master indexes including standards for duplicate management;
- automated warnings and standard report generation; and
- disconnection, investigation and sanctions for misuse.

Management data

Information management standards are required to manage issues such as:

- the need for patients to be informed about the use of de-identified data;
- the legislative cover for such use;
- business rules and 'need to know' guidelines governing access, linkage to other data and limitations on analysis and publication;
- logging of access to potentially identifiable data and sanctions against unauthorised use or linkage; and
- accreditation, review or audit of data management practice by patient advocates, data custodians and statistical experts.

These need to be supported by system standards relating to:

- system architecture and connectivity;
- data warehouse management and business rules including role based 'need to know clearances' and audited access logging;
- datamart/report access authorisation;
- any common case or unique patient identifiers contained in the system;
- metadata maintenance across common data elements;
- disconnection and investigation of unauthorised queries; and
- sanctions against misuse.

3. Research access

Information management standards are required to manage issues such as:

- the need to ensure that general patient descriptors in individual records or 'case' histories are pseudonymised;
- logging of access to identifiable data and sanctions against unauthorised use or linkage;
- business rules to protect case anonymity during analysis and in published results;

- ethics clearance to weigh risk of access against potential benefit; and
- audited disposal conditions and/or periodical review of data holdings.

These need to be supported by system standards relating to:

- conformed, generalised and encrypted data elements;
- project level ‘need to know’ data access screens;
- restriction and logging of access to data linkage; and
- disconnection and disqualification for unauthorised queries.

These issues are summarised in Table 2.

Table 2 Standards issues in relation to purpose and information management area

	WHAT IS RECORDED How Why For whom	SYSTEM Media and formats Storage Transmission
CLINICAL RECORD Health history of a patient	Clinical content Privacy Retention/disposal policy Patient access to records Review/audit of practice	System security Communications standards Patient master index Warning/report generation. Sanctions for misuse
MANAGEMENT DATA Monitor the effectiveness, quality-safety of care	Patients informed of deidentified data use Legislation Business rules on access and linkage Access to identifiable data logging and sanctions Accreditation/review/audit of practice	System architecture and connectivity Data warehouse management Datamart/report access Common case identifiers Metadata maintenance Investigation of unauthorised queries Sanctions for misuse
RESEARCH ACCESS Treatment best practice Epidemiology	Patient data pseudonymised Access to identifiable data logged – sanctions for unauthorised use, linkage Business rules to protect case anonymity Ethics clearance to weigh risk of access against potential benefit Audited disposal conditions and/or periodical review of data holdings	Encrypted data elements. Project level ‘need to know’ access screens Linkage access strictly restricted and logged Disconnection and disqualification for unauthorised queries

So what is (not) new?

Notwithstanding the complex matrix of standards that is called for by modern information technology, there is much that is not new about the health information environment. There have always been patient records and there has always been the need to balance management reporting requirements with the need to protect privacy.

Traditionally this balance has been managed by people, supported by professional standards and more recently by legislation. What is new is that improved technology enables more information to be made available more quickly and more easily. However, the same technological improvements also enable information to be stored more securely and access to be monitored more transparently.

The goal of current standards work is not to alter this balance but to achieve improvements on all three fronts:

- improved patient histories;
- improved accountability (eg. for quality, safety and productivity); and
- improved privacy.

This means that information standards themselves must be subject to a process of continuous improvement.

In particular:

- They must be *responsive* to the current needs of users and to available technologies in the marketplace.
- They must be *realistic* in terms of both the cost of adapting existing information systems and the feasibility of change management from existing methodologies.
- They must be *revisable* as new innovations occur, as compliance improves (ie. the 'bar' of performance can be raised) and as the information policy environment changes. This policy environment is itself in a state of rapid development and changes in aspirations, opportunities and restrictions are not always predictable.

SHARING INFORMATIONS SECURELY – FUTURE DIRECTIONS

Sharing information securely

Mr John Lewis

Senior Manager, KPMG Consulting

Abstract

If the goal of the national *Health Online* strategy to share patient information across settings and jurisdictions for improved health outcomes is to be achieved, there must be in place a comprehensive security framework that implements privacy legislation and associated codes of practice.

The IT14/4 Security Working Group is developing a framework for Australian health information security. It is building on the excellent work already done in the wider e-commerce community by IT12, which produced AS/NZS4444 Information Security Management Standard.

The IT14/4 working group recognises the health industry has particular security issues and as a result is developing an implementation guide to AS/NZ4444 for the industry. In addressing the particular security needs of the health industry, it is important not to ‘re-invent the wheel’ and duplicate existing work. Hence, the IT14/4 Working Group is reviewing the AS/NZ4444 Security Management Standard and applying it to the health industry.

The presentation will describe the issues the Working Group has encountered in developing a Health Information Security Implementation Guide and describe the approaches taken to address them.

Sharing information securely

Professor Branko Cesnik

Director, Centre for Medical Informatics, Monash University

Abstract

The Southern Health Care Network (SHCN) Smartcard trial has its origins in the SHCN coordinated care trial. Smartcard was envisaged as a solution to problem of collecting and sharing information in a distributed data system, where providers used a variety of information systems with no common standards or definition. The intention was to use Smartcard technology for 'key' and 'carrier' functions, while safeguarding consumer privacy in relation to their health data.

Smartcard was not used in the Co-ordinated Care Trial, largely due to the time required for technical development of the card and its system interfaces, and the need to ensure that privacy issues were satisfactorily resolved. The Smartcard Trial ran independently and ended its live phase in December 1999. The trial provided the opportunity to test a number of issues regarding use of Smartcards in the health environment. The evaluation has been completed and the final report is in preparation.

The final report containing a detailed analysis of trial outcomes and pointers for future use will be available through State and Commonwealth web sites from late July/early August 2000.

Sharing information securely

Dr Tom Stubbs

Chief Information Officer

South Australian Department of Human Services

Abstract

In the area of ‘security and authentication’ much emphasis is obviously placed on the technical aspects. However the vexed question of ‘unique identifiers’ raises similar issues as they relate to both consumers and data.

At the two extremes of the debate there are those who raise the spectre of the Australia Card debate and those who claim an identifier as the panacea for all problems. As always, the truth is somewhere in between, although the hypothesis in this discussion is unashamedly that we must have one.

RESEARCH AND DEVELOPMENT – THE WAY FORWARD

The information needs of medical researchers

Dr Jack Best

Chair, Strategic Research Development Committee

National Health and Medical Research Council

Welcome to our session on 'Research and Development: The Way Forward'. Before I make some remarks on the topic, I would like to introduce the other speakers for this session. We are fortunate to have with us this afternoon Professor Peter Yellowlees from the Centre for Online Health at the University of Queensland, Professor Enrico Coiera from the Faculty of Medicine at the University of NSW and Ms Anne Davies who is CEO of IBA Technologies — who will also contribute their expertise to this session, and I would like to thank them in advance for their contributions.

Speakers have 15 minutes each to address their topics, followed by a question period of 3 minutes. This will leave us with 15 minutes at the end of the session for general discussion and to identify priorities.

Let me set the scene by making a few remarks based on my experience in the general area of medical research and how to translate new research findings into medicine as it is actually practiced in Australia.

It would be hard to think of an occupation that is more information-intensive than the practice of medicine.

Indeed, drumming in the knowledge considered necessary to produce a doctor is a very drawn-out affair — six years and more compared with three for most other kinds of degrees, for example.

And, many doctors spend a good deal more time acquiring the knowledge necessary to specialise in a particular aspect of medicine.

Then, even when they are let loose to practice on the populace at large, they are expected to keep up-to-date in their chosen field, for example by reading journals and keeping up with what is considered 'best practice' by their peers.

The field of medical research is even more information-intensive, since often what is trying to be uncovered is new knowledge about cause and effect — against a background of many other potentially confounding influences. In this regard, while medical researchers have come up with some spectacular discoveries over the years — and this is accelerating — often not enough prominence is given to the unsung but medically vital

discovery of our age: that of the double-blind trial (ie where neither the patients nor the researchers know during the trial which patients are being treated with medicines and which with placebos). It is salutary to note that such a valuable tool of scientific medicine is barely 50 years old.

Value of medical research

There is now interesting evidence coming out of the US, undertaken by leading economists, which suggests that the potential returns to medical research are enormous. Murphy and Topel, from the University of Chicago Business School, have, for example, estimated that eliminating deaths from heart disease would generate economic value of US\$48 trillion, while curing cancer would be worth US\$47 trillion. More realistically, reducing the death rate from either of these causes by 20 per cent would be worth around US\$10 trillion to Americans—more than a year's GDP! Of course, that might just mean that we need to spend health dollars combating some other disease — but there would still presumably be considerable gains if the net result was to significantly extend longevity.

These are impressive returns, and provide solid backing for last year's boost in public funding for medical research in this country.

But the challenge is to leverage new knowledge to best effect

Yet, even when the medical researchers come up with various breakthroughs, there is then the considerable challenge of translating their research findings into medicine as it is practiced on a day-to-day basis.

The nature and magnitude of this challenge is indicated by the enormous variability across the country in the care patients with particular conditions receive.

Thus, however good medical researchers become at expanding our 'knowledgebase', we will not get a commensurate return on that investment if new knowledge is not translated into the kind of care Australians receive at the hands of the system.

In spite of proliferating 'best practice' guidelines and increasingly ready access to what researchers are finding out, we cannot say that Australia's health care system has been quick to translate new knowledge into practice. In a real sense the stock of knowledge is being added to too rapidly for the system to cope with — leading to 'information overload' for struggling doctors.

For example, one has to have some sympathy with the general practitioner now occasionally confronted with a patient who has downloaded what he or she regards as the very latest research findings into some condition.

The response of the 'system' has been interesting. Personally, I think we have put the cart before the horse in attempting to get doctors to use computers to increase their

productivity. It was a mistake, in my opinion, to encourage doctors to acquire hardware (ie a computer) before suitable software was available to help make their jobs easier.

For example, it would have been fine if when hardware was installed they could have accessed patient medical records immediately. That would then have reinforced the value of becoming computer literate, because productivity would have been enhanced. As it is, from what I can make out, the options seem to be that they can become the captive of some software firm or surf the Internet in search of help. Either way, it does not necessarily make their day-to-day job easier. If you are going to intervene, in other words, do it in a smart way rather than rushing into the thing because it sounds like the right thing to do.

To my mind, reaching for the technological 'fix' too quickly means all too often shooting yourself in the foot. Instead, before deploying the latest systems or gadgetry we should draw our collective breath and ask the following kinds of questions of the proponents of the latest quick fix:

- Is it generalisable, or will it only work for the enthusiasts rather than the sceptics?
- Is it sustainable, or just something to be piloted and then never heard of again?
- Will community involvement be welcomed, or the 'solution' simply imposed?
- Is it simple and reliable (eg will it work in rural and remote Australia), or is it just designed with the eastern seaboard in mind?

To pass these kinds of tests, doctors will need to be convinced and will need a lot of help if they are to take advantage of new knowledge and new ways of doing the best they can for their patients.

This will involve a sustained effort at retraining and re-educating in non-threatening ways. And it will not always be a negative experience for those prepared to have a go: for example, rural doctors will not feel so isolated if they can use new information and communication technologies to keep in touch with their peers in the cities. At the same time, technology cannot substitute for personal contact. However, given the configuration of this country with its scattered population, personal contact is not always practical. Perhaps I should stop there and see if there are any questions or comments.

Research and development – the way forward

Professor Enrico Coiera

Co-director, Centre for Health Informatics

University of New South Wales

Abstract

The process of research and development in health informatics can be either technology or problem driven, and either pro-active or reactive. At the moment much informatics research and development is reactive and technology driven, which leads to ad hoc developments with little sustainable value in the long run. As worryingly, the capacity for clinicians to adopt technical innovation is often culturally limited, and the best technical solutions can flounder when those who are asked to use them perceive them as an imposition.

The way forward begins by acknowledging how poorly we currently understand the information space in health care and the process of technology adoption, and how little we yet know about either measuring or improving information processes. For example, between 60% and 80% of all information transactions seem to occur not through formal systems that could be computerised, but through person-to-person communication. Within these exchanges we also have some of the largest sources of clinical error and adverse events.

Taking a problem-driven and pro-active approach, we should seek to understand the sources of communication error, and design and then test solutions that include culture and process change, as well as introducing appropriate advanced technologies like mobile voice and data enabled hand-held wireless devices. A rate-limiting step in this process is our profound national skill shortage in health informatics. Without a substantial increase in appropriately qualified people, our national capacity either to introduce the current generation of information technologies or participate in the development of the next generation is critically limited.

Research and development

Ms Ann Davies

Chief Executive Officer

IBA Technologies Limited, Victoria

Abstract

The health IT industry in Australia is accustomed to deploying significant resources into research and development (R&D). IBA Technologies, for example, makes an enormous investment in R&D relative to its income. The talk will broadly describe some of our developments – particularly in e-health – and set them in the context of how we view the healthcare system and our place in it. The key messages will be that e-health is a work in progress, the public sector needs industry to develop the concept to its maximum potential for the health and safety of the community, but revenue models for the private sector are far from clear, so realistic partnerships are required.

EXPORT OF AUSTRALIAN ONLINE HEALTH SERVICES: EXPORTING HEALTH INFORMATION SOLUTIONS TO THE WORLD

Export of Australian online health services

Ms Char Weeks

Relationship Development Manager, Health Communication Network Victoria.

Abstract

Health Communication Network has ventured into the health information solution export market with its acquisitions of knowledge resource companies, MicroInfo and Optology, in the UK. It is also investigating opportunities in Asia.

Venturing from the safety of our own shores into the global e-health community has enabled HCN to embrace a number of challenges, particularly in understanding other cultures, health systems and the way that business is done in other countries. Additional challenges include the transferability of information systems between countries and remote management.

Export of Australian online health services

Ms Yvonne Packbier

CEO, Collaborative Health Informatics Centre

The Collaborative Health Informatics Centre (CHIC) is a national, independent, not-for-profit organisation funded by both the Government and the private sector. It was officially established in 1998 to facilitate better patient outcomes through more effective use of information technology and telecommunications in healthcare. CHIC aims to make it easier for information technology companies and the healthcare industry to conduct business with each other both in Australia and internationally.

CHIC focuses on three key initiatives: acting as an information portal, networker/facilitator, and government outsourcer. CHIC has a client base of over 6000 health information technology professionals with whom communication is maintained primarily through a fortnightly e-mail newsletter (health information technology industry news, events, business opportunities). The organisational website contains a wide array of health information technology information and receives 55,000-75,000 hits per month.

This presentation will provide a snapshot of the exciting opportunities that exist in Australia's growing health information technology sector. The presentation includes an overview of the size of the health information technology sector worldwide and where Australia is placed in relation to the rest of the world. Information about the progress of Australia's health information technology will be explored and the presentation concludes with some suggested actions for Australian health departments and government to take to ensure Australia takes advantage of the health information technology opportunities that currently exist.

Setting the scene: global health information technology

What is happening in Health information technology in the rest of the world and how does Australia fit into this?

As the audience is mainly executive management in the health sector, you will know that Australia is recognised worldwide for its medical training and high level of medical expertise.

And how is Australia positioned in the global world of information technology?

Australia is well known for being innovative and quick with the adoption of information technology.

Australia has a world competitive service sector:

- proportionately more .com.au sites than .com sites in the United States;

- per capita, Australia is amongst the world's highest users of mobile phones and the Internet; and
- most of the Australian information technology companies are small and innovative - they are ideally positioned to provide the software and service in the niche markets that are opening up in the healthcare sector.

Due to Australia's disparate population, innovative methods of delivering healthcare services to remote and rural areas have been developed. Australia now has the largest Telehealth network in the world.

For the first time, we have information available about the size of the information technology usage in healthcare in Australia - as a result of a study done by CHIC at the end of last year (E-Health: An Exploratory Study of Health information technology in Australia and New Zealand).

As a result of the study, CHIC estimates that the total expenditure on health information technology within the public health system will be approximately \$645m this financial year.

Information technology expenditure in the Australian health sector stands at 1.5% of the total budget.

In comparison, the USA figure is 3.5% and UK 2% (although this could possibly be higher given the UK government's recent budget announcements).

What this above diagram does not represent is the trend in information technology investment by the health market and the information technology market. Information technology industry revenues have grown by 135% since 1990 whilst health industry expenditure has not moved significantly.

Overview of the world health information technology markets

The United States is the largest health information technology market in the world. Health care providers began investing in information technology at a very early stage. This has resulted in the United States possessing a great pool of health information technology knowledge – something which Australia can learn from.

For this reason, CHIC has developed close relationships with several key health information technology organisations in the United States - Gartner, Dorenfest and the Healthcare Information Management and Systems Society (HIMSS).

The Asia Pacific Region has tremendous potential as a market for health care technology applications. Not only are Australian companies ideally positioned to access this market themselves, but Australia can also form the base for companies from the USA or Europe who are interested in the burgeoning Asia Pacific market.

Japan is one of the more mature health information technology markets in the Asia Pacific region and it has been estimated that the market is worth close to US \$2.5 billion per annum. Japan has in excess of 9400 hospital (with over 80,000 clinicians) as compared to Australia's 1200 hospitals.

Japan has one of the leading state of the art hospitals in the world at the Kameda Medical Centre: its objective is to provide a 'healing environment' with high technology. This 500-bed hospital has a fully integrated medical record system, which ensures the hospital is paperless and film-less. Each room has Internet capability and each bed is a nursing station.

What you will see from this comparison of Australia with other countries is that:

- Australia is lacking a 'critical mass' because of the very small domestic market and as such, Australian companies have to look globally for other markets.
- Being in the Information Age is very helpful for Australia as the Internet and e-commerce gives Australian companies the economies of scale to reach the 'critical mass' of Health information technology buyers globally.

Due to the small domestic market, Australian companies must pursue the worldwide Health information technology market. Australia has the potential and capacity to do so.

Australian health information technology achievements to-date

A coordinated, national approach has been developed by CHIC to increase collaboration within the industry and reduce the duplication of effort.

CHIC's global reach has been achieved by drawing on the expertise and experience of other government organisations:

- Austrade and its offices in 108 cities across 62 countries
- State government export activities - most of the state governments have offices overseas to assist companies from their state in export activities
- Department of Health & Aged Care - international program - making use of the Memorandums of Understanding that have been signed with many countries
- Department of Industry, Science & Resources - international program
 - This year the French Australia Industrial Research (FAIR) program annual workshops focused on health information technology and due to its health information technology knowledge and contacts, CHIC coordinated the program.
 - ISR is organising the Australian Health Industry Development Forum and is working on the AusMed initiative - CHIC is involved for the information technology component.
- Invest Australia - investment attraction – CHIC is currently targeting the US for investment into Australia
- Department of Communication, Information Technology and the Arts - international program
- National Office for the Information Economy – CHIC has been involved in Telehealth activities

Ambassador - visiting countries

Working as an 'ambassador' for Australia is essential if Australia is to feature on the global health information technology map.

Five years ago the first Australian delegation participated in the largest health information technology conference in the world - the Health Information Management Systems Society (HIMSS) Annual Conference and Exhibition held in the USA. Exhibiting American companies gave little credence to the developments of health information technology in Australia and there was minimal interest by American companies in doing business with Australia.

After five years of work and taking more than 230 delegates to the conference, North American companies are now taking notice of Australian health information technology. In the last two years we have seen 6 presentations by Australians at the conference which is attended by about 18,000 delegates.

CHIC is now the Asia Pacific chapter for the HIMSS organisation and their Board has established an International Taskforce to make their activities more relevant for an international audience.

When dealing with international markets it is important to 'be seen to be around' for several years before credibility can be earned.

For the last two years, CHIC has facilitated a delegation to **Malaysia** and the participation of several companies to exhibit at the annual Hospital conference. This year, CHIC was invited to provide a keynote presentation.

CHIC has been active in the European market having organised workshops in Europe and two best practice site visits of the United Kingdom and Continental Europe. As a result, a smartcard expert visited Australia and shared his knowledge through a seminar in Sydney and in Melbourne.

Ambassador: hosting visitors

People visiting Australia provides an ideal opportunity to showcase Australian expertise and to create links with health information technology experts in other countries.

- CHIC worked with the Department of Health and Aged Care on hosting a delegation of telehealth officials from Thailand.
- CHIC was involved in the organisation of a Japanese delegation to Australian Hospitals.
- In October this year more than 160 senior executives will attend the Japan-Australian Business Council and learn about Health information technology.

Export assistance: information

CHIC has developed services to assist companies to access the health IT market: domestic and internationally.

Companies exporting

Currently about 78% of information technology companies actively involved in the health information technology industry are interested in exporting their products and services with 46% already actively pursuing this.

Many of these companies are at the early stages of international market penetration: 80% of the current exporters are realising less than 10% of their revenues from these activities.

A few companies generate more revenue from their overseas markets than they do from within Australia.

Some examples of companies exporting are:

- Compumedics (sleep disorder monitoring, teleradiology, neurology) this Australian company recently won the national exporters award
- Triple G (laboratory systems) – due to its success, Triple G was recently acquired by a French company
- Integrated Medical Systems (laboratory & radiology systems)

Between them, these companies have successfully penetrated markets in USA, Asia, UK, EU, Russia and Brazil.

More detailed information about what is involved in exporting will be provided by HCN's Char Weeks and MIMS' Tony Firth in the next presentations.

What can health departments do?

Health care in Australia is based on a social system - similar to the UK and Canada. Therefore the government plays a key-role and is the key purchaser of information technology for the health care sector. Governments need to:

- Realise that Australian health information technology solutions are world-class
- Make doing business in Australia easier
 - Encourage partnering with local companies
 - Realise the enormous investments information technology companies have to commit to when responding to tenders
- Realise your investment in information technology will result in companies being around to work with you
 - Several information technology companies have already decided it is too hard to do business in Australia - focusing on other markets in Asia Pacific is easier and better for the business

- Australia being part of the global health information technology sector is not only an opportunity - it is also a threat: Australia has to pay attention in making sure companies want to do business here!

Government involvement is essential to make sure we will have companies in Australia to do business with - and not all of them are only pursuing global opportunities.

EMPOWERING CONSUMERS AND COMMUNITIES FOR BETTER HEALTH

The future of health information – a social commentary

Ms Geraldine Doogue

Journalist, Broadcaster and Social Commentator

Ladies and gentlemen, thank you very much for inviting me today....it's a challenging task you've laid on me, to provide some commentary on what lies ahead combining the health of Australians and the electronic revolution in our midst.

I've taken as my brief to try to be the representative of ordinary Australians in thinking through this.

To the extent that my job gives me access to a wide range of views and information, I'm not typical of that ordinary Australian. But I am in that I'm a relatively disinterested observer. I don't represent any interest group. I'm not partisan on some of the issues at stake here and I'd have what I'd describe as pretty orthodox desires for privacy to remain a central right and for the ethical handling of sensitive information – nothing particularly staggering there. In fact others may be far more anxious than I on privacy issues.

Confidentiality would have to remain a sacred, central tenet.

Clearly we are living through times of a paradigm shift, certainly the equal of the Industrial Revolution. We are cursed, in a sense, by 'living in interesting times', cursed maybe to be consigned to change being a constant for possibly the rest of my life (I'm now 48)maybe not. I'm not sure any longer but have stopped worrying about that. I do believe though that one of the enduring features of human beings is that they do prefer peace-of-mind in their daily lives, not boredom but not the roller-coaster ride that's been our lot of late.

So yes, I do wish for my children a more tranquil world, where some new rules have been established, that enable more clear decision-making with codes that last more than one year. Jeff Kennett addressed a Brisbane Businessmen's Club luncheon a few years back and warned of 30 years of constant change! I wonder now (a) if he was right and (b) if he quite anticipated the changes that were to come to him!

Anyway, we live in the time in which we live, with all its benefits and challenges. The key challenge, as I see it, is to remain a rational citizen, to remain engaged and to consciously try to discern what is in the best interests of us, as individuals and the nation, to consider the trade-off and if needs be, err in favour of the greater good.

Now if you ask me, in my position as media commentator, and the recipient of hundreds of viewers' and listeners' letters, whether this is the prevailing attitude of my fellow Australians. I'd say probably NOT. I'd say there are levels of real exhaustion around change and a growing tussle within people's minds and hearts about the effort to stay rational, in the face of all sorts of new information and demands for them to shift ground.

The demands on my own profession, the media, during an era like ours, are considerable.

We have to report fairly and accurately. But really that's the easy part. We have to highlight competence as well as incompetence, in my view, and that hasn't really been our *modus operandi*. I was brought up being told to ensure there was always some drama in my presentations, which invariably became an emphasis on conflict....with always a protagonist and antagonist; and really an emphasis on problems, guided by the application of a sceptical mindset that said "hey, wait a minute...what joker's proposing this?" before it said... "how interesting...tell me more." Or alternatively the other key part of our armoury: "who's to blame for what's gone wrong?"

I must stress, this has its place in the Fourth Estate's duties. But, I would say that at a time of great change such as we're living through, it's also vital to explore new ideas, to rigorously question those proposing them, to search out models of competence, to not be disproportionately fearful but instead confident that I, as a reporter acting on behalf of the public, have the skills to test, reasonably, the key participants.

To lay out the dilemmas in a way which encourages people to remain, as I said, engaged in the natural drama of life.

Because a community where ordinary people are more, rather than less, inclined to make decisions about change, rather than merely drifting towards it, or worse still, being dragged there, is a vastly happier community...a community where that key commodity, SOCIAL TRUST, is augmented. And a community where irrational scare-mongering finds less fertile ground.

It seems to me that with the complexity of decisions you, as a group, are trying to preside over right now, one of the things you need most is a community ready to examine things with an open mind....to help you in your deliberations, to act as collaborators rather than passive recipients, whom you deem to be down the totem pole of power.

Anyway, judging by the quality of work distributed thus far by the National Electronic Health Records Taskforce, neglect and high-handedness doesn't seem to be a hallmark of the people concerned. For that I applaud you.

There's another aspect to this. Because of the sheer amount of change, you possibly can't necessarily speak with total surety about some of the outcomes of the work you're doing.

I sense that planners at the moment find themselves in slightly delicate positions. Only the out-and-out true believers (and their passion can be really quite attractive by the way) can say categorically that they know exactly which way developments will proceed...or speculate with total confidence about benign outcomes drawn from benign intent.

Clearly, it's just not possible to imagine these days some of the applications of available technology or to forecast all the permutations of how people's lives will be affected. So to that extent, introducing change can pre-dispose change agents to the charge of being merely spin-doctors, manipulators. The former Liberal Party chief Andrew Robb is well-used to interpreting voter intentions and seeing behind the obvious. He believes most people do accept that most others are acting out of self-interest – far better then to identify it rather than pretend it doesn't exist. They're quite suspicious of those who claim it's not there.

What I feel quite strongly about – and would really encourage you to consider – is how you best promote two essential qualities necessary for democratic communities to thrive: to build in appropriate checks and balances and then to boost people's trust in those systems, confident in the belief that they are designed for the overall good of the greatest number and that they basically deliver.

Now as you know, as word has genuinely started to spread about health online or e-health, and where it might head, all sorts of people have started to grapple with the implications.

So that you have people like Dr. Alexander Bennett from Cooroy, writing to Australian Doctor in May this year, talking of centralised databases as “the greatest threat to family medicine since the advent of Medicare and the greatest threat to personal freedom since the Australia Card idea was thrown out a few years ago”.

And he goes on to make a really quite passionate plea for his own services. “Prior to the introduction of fast, throughput medicine, bulk-billing and doctor shopping brought about by Medicare, the family doctor was the repository of the Big Picture for each patient.”

“Put simply, in whom do you place the greater trust...in the human face of your family doctor whom you can personally keep accountable for your medical record or the faceless bureaucrat in Canberra, controlling the database with your information on it?”

Or you have the excellent reports of someone like Karen Kissane, doing a good job in the Sunday Age in June, laying out all the elements of the decision at hand....but dare I say, in such a long article that you had to be seriously committed to read it all.

And what did she lead off with? This quite arresting and sadly, true, story of what's possible.

She wrote of a New Zealand tragedy, where a girl was rushed to hospital with complications following an abortion. She had begged staff to shield her from a relative working in the hospital who might tell her conservative Indian family.

The staff did put the girl in a different ward to where the relative, a nurse, was stationed, but failed to tell the girl she had the right to a 'manual' admission, with her details kept in an old-fashioned paper file.

Instead, her case was recorded on the hospital's computer database where it was found by her relative, allegedly in the habit of trawling the system for familiar names.

The result, said the New Zealand Privacy Commissioner Bruce Slane, was "complete breakdown in family relations", illustrating the sheer sensitivity of health information and the sometimes devastating consequences of its improper release...as well as the ease with which health databases could be violated, said Kissane.

...who went on to quote people like Dr. Sam Heard, from the Northern Territory Clinical School of Medicine at Flinders University....he's been working on what he calls the Good Electronic Health Record for 13 years now. Databases worry him, the more people with access to a system and the larger the database, the more valuable it is and the more at risk it is, he said.

Made sense. As someone I interviewed on this said, the characteristic about our greater capacities in this field is not so much in collection but in easier retrieval. However Sunday Age readers were given the outlines of a case where the size of a national storage facility could prove to be a distinct advantage, particularly in our increasingly mobile society.

This was an imaginary scenario quoted in a recent Medical Journal of Australia, which I found quite useful. It talked of Mr. Smith, a truck driver, away on work, seeing a GP and complaining of severe headaches. He asked for strong pain relief.

What the doctor saw in front of him was an unkempt man from out of town, requesting a drug of addiction. With Mr. Smith's permission the GP called up his medications history to check that Mr. Smith had not been misusing prescribed painkillers...which he hadn't.

But...a prompt pops up on the screen telling the doctor that the national adverse events register has recently detected an interaction between two drugs Mr. Smith was taking for other conditions. Surveillance of the national health records system had found that people taking both often suffered hypertension and severe headaches.

The GP prescribed alternative medication for Mr. Smith. Happy ending all round!

In other words, there are risks and rewards.

It's been ever thus but somehow, this is thrust in our faces so much these days and my sense is that as the years of change keep coming, we tend to feel that posing this very dichotomy is a bit of a ruse in itself: that we really have little or no choice with these big forces and that we've got to cop all the risks with little surety at all about the rewards.

And what lots of social research shows is that along with that sense of impotence can come sullenness, resistance, irrationality...often totally counter-productive behaviour, particularly if you feel it's being DONE to you without your permission by someone else...who's got more anyway. The politics of envy and alive and well.

And as they say about even paranoids having genuine enemies! It's naturally reasonable to be vigilant. People like Professor Reg Whittaker, in his book *The End of Privacy* puts it brilliantly.

Geoffrey Barker wrote quite an interesting piece just the other day on Whittaker's warnings about public and private data banks providing an extraordinary catalogue of information about personal, financial, insurance, welfare, utility use, real estate, entertainment, consumer, employment education and legal data on individuals.

Why is so little fuss made about the collection and sale of this information by marketers, asked Whittaker?

"Because most people perceive they gain the benefit of inclusion in the consumer economy. Those who possess bank, credit, debit and cash cards are empowered but this depends on a disempowerment of others. The ability to extend credit to the creditworthy is made possible by the ability to identify and exclude the risky," he argues.

Now this is not, strictly speaking, pertinent to what you're considering with electronic health information. But your changes and possibilities are happening within that overall climate and so heavily influence the reception of innovations like HealthConnect...being spoken of yesterday I might add, at the Labor Conference as having the ability to revolutionise health care.

So attitudes to the changes you're interested in have been softened up by consumers' interaction with marketers, banks, spruikers of various sorts, also offering revolutionary developments in this and that field of endeavour.

From my standpoint and from exposure to other industries with related challenges, like the biotechnology industries, a couple of things are vital when trying to encourage an optimistic, public mood.

1. That people do genuinely believe they have some choices, and that these are not ersatz choices – those you have when you don't really have a choice.

2. That governments are seen to be acting as honest brokers in all this, regulating wisely and with a view to protecting qualities of equity and social cohesion, which are explicitly stated.

In Australia mercifully – as opposed to the USA from which I’ve just returned – there is still, despite some counter-indications, a real belief in my view that government is capable of acting on the group’s behalf and of being a good police-person.

I think that belief is simply a vital tool in smoothing the transition to a new era.

Another key observation is ordinary people’s gathering desire to tap into unfiltered information in a number of areas but particularly when it comes to their health.

The experience of the National Library of Medicine in the United States with its Med-Line site is quite illuminating.

They now have literally millions of regular hits, I gather, for quite raw data that it had been assumed beforehand, might have been inaccessible to the general public – or perceived so by them.

In fact, my colleague Norman Swan, from Radio National’s Health Report, has noticed exactly the same phenomenon.

It has the highest number of requests for information on-line – different by mail I think but certainly on-line – of any Radio National site. And he tells me he can see a steadily growing appetite for information, challenging any residual arrogance Norman might still possess from his medical training too!

Because people without a Fellowship are seeking quite arcane details of studies and research projects.

He sees it as a developing notion of control over one’s fate...certainly a presumption that untrained people can educate themselves, using modern tools, to establish something more like a partnership between them and the health profession than used to be the case.

We’ve also commented for some time now at LM how our site and our resources are routinely used by listeners almost as a modern, sophisticated library...with already skilled workers requesting very selective information for their own research purposes to better skill themselves.

In fact, it’s quite a policy issue for us at Radio National and something like LM. Is it possible to imagine a world where the radio broadcast is a mere sidebar to the main event, on-line services: that it’s merely the shop window-front?

But I don't know. Greg Hywood, the editor-in-chief of the Sydney Morning Herald, says managing in effect two cultures simultaneously at Fairfax, the traditional product and the new on-line world for payers, is his biggest challenge.

Clearly this is about issues of CONTROL at base: patients, individuals have been fed lots of different marketing and intellectual lines related to the average Joe Blow potentially having much more control over their lives...the democratising influence of the Net.

Paradoxically, this concept is on offer at precisely the same time that many of us feel control is slipping from us...that's a key complaint. But not by all...there are no uniform experiences any more. Depending on your degree of feeling linked will rest your sense of whether you're being spun a line.

As Andrew Robb put it recently: what drives people's anxiety is fear that those advocating change have most to gain from it!

So deep down, an invitation to gain more control, not to have to rely on mediators is rather appealing.

I think it could make HealthConnect (or whatever the system turns out to be named) a considerable drawcard on exactly these grounds.

Which is exactly why it'll be opposed by some other group, who will see themselves losing control.

Managing that central dance will take great finesse.

Clearly the timing of developments will be crucial: the building-blocks of adequate well drafted legislation; the explicit presence of someone in charge; the unerring sense that this modern development can be applied for the benefit of average people...people having free choice at all times, confidentiality emphasised...and maybe to take a leaf out of the Defence Review's experience and maybe visibly consult around this wide brown land.

They're on a 30-site whistle stop tour around the country listening to people's wide-ranging views about our defence arrangements, hearing their apparently often very well formed views on what is being pitched as a crucial part of our national identity and incidentally providing great opportunities for programs like Life Matters, who proposes this as one of our Wednesday Talkbacks in about 3 weeks time.

Bringing Government decisions close to the people who will live with them.

Now I'd like to draw to a close with a bit of history-giving perspective.

Personally I find it helpful and ultimately energy giving to stand back just occasionally and see if there are precedents for what we're living through...history never exactly

repeats itself and of course some claim everything is brand new these days...but I doubt it.

We may think the information revolution – in which you are here to play a significant role – is a sort of ground zero, a tabula rasa on which some of the more privileged of us will write and leave our mark.

But a lot of misguided guesswork will occur and a lot of efforts won't survive ... just look at the last tectonic shift, back 200 years ago during the onset of the Industrial Revolution.

The American economics commentator Peter Drucker wrote an absolutely marvellous piece on this in the Atlantic Monthly late last year.

He essentially argues that the key changes to flow from the Industrial Revolution related to changed conduct and people's perceptions of what was possible in human affairs ...new 'mental geography', as he puts it, far more significant than mere technology ...fascinating thesis about human relationships.

The Information Revolution, he suggests, is now at the point at which the Industrial Revolution was in the early 1820s...that was 40 years before James Watt's improved steam engine was first applied in 1785, to the spinning of cotton.

Watt certainly never imagined what it would trigger and, Drucker said, the Industrial Revolution whizzed along in terms of change, every bit as fast as the Information Revolution "there really is not much that is new under the sun".

Who could have imagined this increased capacity for cotton textiles would give rise to the factory, the 'working-class', the entrepreneur was created – it revived slavery, which was on the decline: it had a huge impact on the family.

But in its first half-century, the Industrial Revolution only mechanised the production of goods that were already in existence.

Then in 1829, came the product truly without precedent – the railroad, forever changing the economy, society and politics.

This rapidly changed what Drucker calls the mental geography of people, who for the first time in history had true mobility...leading to whole new industries that had nothing to do with steam engines like electricity, the telegraph, photography, public health became a major growth industry – cities offered a healthier environment than the countryside – new social institutions: modern postal service, daily papers, investment banking.

Now he would say thus far, the Info Revolution has...brilliantly...routinised traditional processes in vast numbers of areas.

But...what is to be the information revolution's railroad?

Well he says it's e-business! Electronic transmission of information...

Because it changes the social power patterns...and that takes you and me into whole new realms that actually at this stage we can only guess at!

Will leadership be maintained differently? Will prestige and hierarchies be turned upside down? Will knowledge and the right to control it be seen altogether differently? Will capital and labour seem incredibly crude slogans?

That's what is, I suspect, at stake, in what you're pondering.

Or as Michael Powell, Colin Powell's son, a Federal Communications Commissioner in the US, told a conference I attended recently: "In my experience within the last 5 years" he said "you can pretty safely assume the claims for straight forward technological changes in the future are being over estimated...but those for the impact on our institutions and society are being underestimated."

Your great challenge, as I see it, is to remember that prediction as you navigate those risk/reward possibilities and try to engage as many of us as possible in influencing what comes next.

EMPOWERING CONSUMERS AND COMMUNITIES FOR BETTER HEALTH - E-HEALTH FOR CONSUMERS – BENEFITS AND RISKS

Empowering consumers and communities for better health

Mr Matthew Blackmore

Executive Director, Consumers' Health Forum of Australia

I've been asked this morning to speak with you about e-health for consumers - the benefits and risks. It sounds new and inviting – almost sexy doesn't it? E-health. The information economy has spawned a whole new language – e-business, e-commerce, B2B and let's not forget B2C. At the Consumers' Health Forum, we're attempting to ensure that we maximise our C2C.

So is e-health a magic bullet to solve whatever health problems we have as a society - or will the love affair with the new 'information economy' give way to disillusionment and a return to the 'old economy' – personal computers in hospitals and medical practices spewing out reams of paper that no one will use and is filed away to gather dust.

I'd like to take a step back for a moment and see whether history can give us some pointers in addressing and managing the challenges of the information age for the benefit of consumers, both individually and collectively.

In the industrial revolution, society was rapidly transformed from an agrarian rural society to an urban one based on manufacturing. At the heart of this change was the development of the steam engine and a series of remarkable inventions in textile manufacturing. As John Kenneth Galbraith has observed 'Clothing was a major service to ostentation by the rich, an indispensable utility for the poor. The hand spinning and weaving of cloth were infinitely tedious, costly processes; the purchase of a coat by the average citizen was an action comparable in modern times with the purchase of an automobile or even a house. The new machines took the manufacture of cloth out of the household and into the mills and made the product cheap – an item of mass consumption.'

And what of the downsides? In the early days of the Industrial Revolution, the new urban environments were unsanitary and disease and illness flourished. Galbraith has observed in his book *The Age of Uncertainty* that cities were 'not grand, not beautiful, not even solid but something mean, ill built and dirty. The Industrial City became the characteristic city, and all cities came to be thought somewhat sordid.'

In the atomic age we were able to split the atom, end a war and provide cheap energy. But it came at a price – radioactive contamination leading to illness and disease. Years later we are left to remedy the foolhardiness of earlier times – the clean up of Maralinga,

the desolation of Chernobyl and now the closure of most of the nuclear power stations in Germany.

In the space age we left the earth's gravitational field and advanced our knowledge of the universe. The quest for space led to a range of scientific breakthroughs – for consumers, new plastics and synthetic fibres are just two of the direct benefits of the space age.

But it too has come at a price and the almost indestructible plastics now pollute our oceans and clog our waterways. In some small way, the space age has left a legacy that we have only just begun to address.

And what of the information age? Our information needs, and the speed with which we want that information, have both increased. Information controls our life. The letter has given way to e-mail and information seeking for work and pleasure in libraries has given way to information seeking on the Internet. Our PC and mobile phone are the new tools.

There are, of course, downsides with these tools from the information age. Our mobile phones may give us cancer and our working life grinds to a halt when the e-mail system or office network crashes. A colleague commented to me recently that she was unable to do any work for the day as the office computer network had crashed. We have come to rely on technology and feel completely lost without it.

So what has all this to do with e-health? These examples are really a round about way of saying that change and innovation can bring real benefits for consumers. But we need to acknowledge that change often has its downsides and risks - for consumers and others - and the challenge in the information age is to identify the actual and potential risks of that change (or as Geraldine Doogue said earlier this morning, to 'lay out the challenges') and build knowledge systems and pass laws to minimise those risks. That is, a roll out of e-health initiatives needs to go hand in hand with effective monitoring and evaluation that is responsive to consumer needs and delivers ongoing improvement in health outcomes. For that is what the aim of any e-health initiatives should be – to improve health outcomes for consumers, both individually and at a population level – in a cost effective way.

So what are the benefits for consumers in the new information age – the age that brings us the electronic health record, medication management systems, telehealth, health information from the Internet, triage and health information call centres, clinical decision support programs and a host of other initiatives and applications?

The most obvious benefit for Australian consumers is access to the Internet. The Internet is providing access to an unprecedented amount of health information. While many health care providers are less than welcoming of their patients who visit the surgery armed with reams of paper downloaded from the Internet, it is one way to provide health information to consumers quickly and inexpensively. Governments and consumer organisations have seen the potential and are actively engaged in ways to ensure consumers have access to reliable, high quality health information. The Commonwealth

has established its *HealthInsite* portal and consumer organisations are working with their members to assist consumers develop the skills and knowledge to recognise quality information on the Internet when they see it. And the consumer who visits their health professional with a stack of downloaded Internet material has given that health provider an excellent opportunity to work in partnership by engaging in a real dialogue. Yes, the Internet has the potential to empower consumers and relationships with their health care providers.

Health triage call centres are also part of the e-health information revolution benefiting consumers. How many consumer visits to health professionals and Accident and Emergency Departments are unnecessary? As a community, we all pay the price for this over-servicing. For consumers waiting in Accident and Emergency Departments for relatively minor problems, the experience is alienating and frustrating, but often they are unaware of any other options. A health call centre that gives health advice or simply information about the nearest bulk billing surgery may avoid that unnecessary visit to the Accident and Emergency Department.

For example, *Healthwise*, a non-profit consumer health information company in Idaho, USA (which Kate Moore spoke about at this Conference yesterday) reduced doctor visits and Accident and Emergency visits by 30% and 15% respectively in that State in the late 1990s. This was achieved by providing all residents with a healthcare manual and freecall telephone support staffed by trained nurses who were able to use the *Healthwise* knowledge base. This knowledge base includes evidence based consumer friendly information backed up by clinical practice guidelines. Many large health insurers in the US now use *Healthwise*. Health outcomes have not been compromised, costs have been contained and consumers empowered.

Medication management systems can also assist consumers. Such systems have the potential to provide consumer medicine information in doctors surgeries and pharmacies, reduce adverse events by improving prescription legibility, reduce adverse events by links to allergy alert systems that minimise the prescribing of medications that are contraindicated. Medication management systems can provide the prescriber with information about medications that may have been prescribed by others. It gives the consumer the opportunity to discuss with their doctor or pharmacist the range of medications that they are taking. Consumers with chronic conditions taking multiple medications may be unable to recall all their medications in discussion with their doctor or pharmacist. Medication management systems can thus empower consumers by both providing information to the consumer and by informing the consumer-provider partnership.

E-health can improve the integration of care to consumers by linking information from a variety of sources and making that information accessible to the primary health care provider or care coordinator. This can be empowering for consumers, especially with discharge plans, where consumers would otherwise have to discuss the actions of other health professionals involved in their care to inform their primary health care provider or care coordinator, rather than discussing problems and opportunities after discharge in an

informed way. This was not possible for consumers in one reported study in the US, where 25% of discharge summaries never arrived, and of the ones that did arrive, 75% were delayed by an average of 25.3 days. Not very empowering.

E-health can improve the evidence base of clinical decision making through decision support software. There is considerable evidence from both here and the US that the evidence base of routine medical care is low. For example, one study in 1990 reported in the New England Journal of Medicine concluded that less than 20% of routine medical practice had its basis in published scientific research. This was consistent with earlier studies. In Australia, there is considerable evidence of incredibly wide variation in surgical procedures leading to the conclusion that the evidence base supporting many surgical interventions may be low.

This does not mean that the rest is wrong, simply that it may not represent the best in patient care. There may be reasons for such variation – the complexity of information, lack of available evidence, subjective judgement, enthusiasm for unproven methods and human error. As one commentator has said, the ‘complexity of modern medicine exceeds the capacity of the unaided human mind’. In one study in the US, decision support software was used to implement antibiotic practice guidelines. It reduced overall antibiotic use by 22%, resulted in an almost 50% fall in mortality rates, adverse drug events fell by 30% and the percentage of patients receiving appropriately timed pre-operative antibiotics increased from 40% to 99%.

How is the use of decision support software empowering for consumers? It’s empowering because it takes the mystique away from the doctor patient relationship, reduces variation in practice and results in better health outcomes. That’s empowering.

E-health has a role in preventing illness. For example, a study published in the New England Journal of Medicine in 1993 estimated that about 25,000 deaths could be prevented each year in the US from three illnesses where vaccine use is low – influenza, Pneumococcal infection and Hepatitis B. E-health has the potential to improve vaccination rates and other preventive care measures by way of reminders – to both patient and doctor – based on information contained in an electronic health or medical record. This can be empowering as it gives the consumer advance notice and time to reflect on the decision to vaccinate or not.

Electronic health records are likely to result in improved record keeping as health record keeping will become one of partnership, leading to a better understanding by both consumer and health professional about what is contained in the medical record and why. That must be empowering. This consumer access also means a more accurate medical record.

E-health can offer integration of hospital electronic record keeping, allowing for the easier compilation of hospital report cards. Hospital report cards are empowering as they allow consumers to choose a hospital of their choice based on their interpretation of quality or what is important for them.

E-health has the ability to provide an incredible amount of information about the health system to consumers – lists of doctors by special interest, their hours of operation, fees and charges and other information such as professional disciplinary information. Much of this type of information could be provided here and now by manual means. E-health simply offers a quicker, more cost effective, accessible way of providing it to a range of users, including consumers. That's empowering.

Better access to information by all involved – consumers accessing their complete medical record, doctors accessing radiology, pathology and discharge plans more quickly and easily, hospitals accessing medication regimes in emergencies – all this has the potential to empower the consumer through improving the consumer-health professional relationship.

So what of the risks? Not surprisingly, there are many real and potential risks for consumers in the e-health arena.

E-health makes it much more likely that consumer health information will be available to a wider audience, making privacy a central concern for consumers. The apparent lack of sensitivity, as reported in the media, by the Taxation Commissioner in relation to the release of the private address and telephone details of Australian Business Number (ABN) holders demonstrates to consumers that Governments and public servants still have some way to go in recognising and addressing this central issue. And of taking it seriously.

Security is a related issue. For any e-health initiative to succeed in the longer term, the technology and communications must be secure. The recent breach of security at the Australian Taxation Office, again in relation to ABN numbers, is a pointer that more needs to be done. Another example comes from Comcare, the Commonwealth's workers compensation authority. Health information about people and cases before the Administrative Appeals Tribunal was taken from a stolen personal computer and made public in the 1990s. Security has many manifestations and is not simply a matter about the security of the communications or software, but can be about physical security and processes.

Consumers also want appropriate use of e-health initiatives – that is, that health information will not be used inappropriately by Government and private sector agencies. One is reminded here of the notification on police networks in Victoria in the early 1990s of the names of persons suspected of being HIV positive. This was not even about people living with HIV – it was about people **suspected** of being HIV positive. This concern goes to the core of building trust with the community, which some speakers have already mentioned at this Conference.

The increasing use of technology may have adverse effects for the doctor patient relationship. For example, one study reported in the British Medical Journal in 1995 suggested that PC use by doctors led to an increase in doctor initiated medical content in

the consultation at the expense of patient initiated social content. This is significant because that social interaction can be a clue to some underlying medical or health problem.

The new technology also increases the capacity to discriminate. For example, the Health Insurance Commission has a program of tracking so called 'doctor shoppers'. The HIC acknowledges that it would invariably identify consumers who were very sick and therefore making a high demand on the health system – but no action would be taken. Nevertheless, they would be identified as high medical care users with the potential for discrimination.

I believe that the way forward is clear. We need a set of principles – consumer focussed principles – to guide us on the road to e-health nirvana.

The first is the paramount importance of consumer participation in the design, monitoring and evaluation of e-health initiatives. Meredith Carter mentioned this yesterday. It is important that health providers and policy makers develop consumer centred and consumer friendly systems and that this be done in consultation with consumers. This will give consumers confidence that systems are being developed for them and the community.

The second is an enforceable regime of penalties for breach of a consumer's privacy or a breach of any guidelines under which initiatives such as medication management systems or electronic health records operate. The sanctions must be clear and unambiguous with tough penalties for breaches.

The third is consumer access to the information that is being collected. There are published studies that show up to 35% of medical records contain factual errors and consumer access and ability to amend factually incorrect information is vital. But its more than this – if consumer fears of 'big brother' are to addressed, consumers need to know what information is collected, who has access to it and why.

In conclusion, I'd like to return to history. When Christopher Columbus returned from the New World he returned a hero. Missionaries were dispatched and gold returned. A triumph all around. Except for the indigenous population who were all but wiped out by warfare and disease. Let's not go to the new brave new e-health world if what we find is technology conquering consumers rather than technology working with consumers to improve knowledge and understanding. Because knowledge and understanding is what will improve our health outcomes. Thank you.

A NATIONAL APPROACH TO ELECTRONIC HEALTH RECORDS

A national approach to electronic health records

Ms Lynelle Briggs

First Assistant Secretary, Portfolio Strategies Division

Commonwealth Department of Health and Aged Care

Good morning. I am delighted to have the opportunity to speak to you today about electronic health records. The potential of electronic health records to improve care outcomes for Australians, and to support decision-making by health care providers, makes this a very exciting area to be working in.

Electronic health records are a major issue. Other countries are also grappling with them. We only have to look at sectors such as banking and insurance, which now rely on electronic records in their everyday business, to see that the adoption and use of electronic health records by the health sector is inevitable. If we were to look ahead ten years, it is a fair expectation that electronic health records will be considered a routine part of health care delivery.

The current interest in electronic records within the health sector has created a unique opportunity for the Government to work with relevant groups to implement policies that will allow the health sector to gain maximum advantage from their adoption. However, if electronic records were adopted in an ad hoc fashion across the health sector, it is likely that work will be duplicated and incompatible systems created. To avoid this, the Australian Health Ministers established the National Electronic Health Records Taskforce, of which I was the Chair.

Today I would like to talk to you about the Taskforce's report, which was endorsed by the Health Ministers last week, and to look ahead to see where we need to focus our efforts.

I will address five issues central to the recommendations of the Taskforce, however, before dealing with them, I would like to give you some more background on the origins and work of the Taskforce.

National Electronic Health Records Taskforce

The purpose of the Taskforce was to bring a coordinated national approach to electronic health record systems and to avoid the potential for incompatible systems and duplication. The Taskforce included representatives from the Commonwealth, State and Territory Governments, the private sector and health informatics experts. Its objectives were to:

- develop the framework for a national electronic health record system; and
- recommend a way ahead to Australian Health Ministers in sufficient detail to enable them to make decisions about committing resources.

The Taskforce drew on information from a wide range of sources, including:

- commissioned reports;
- public submissions;
- feedback and information sessions; and
- briefings prepared by Taskforce members.

The Taskforce has completed its report. It was presented to the National Health Information Management Advisory Council in June before going to the Australian Health Ministers' Conference last week, where it was unanimously endorsed.

The report is now available and you should all have a copy. The wealth of supporting material produced for the Taskforce, including many of the written submissions and other briefing papers, has been published on the Taskforce website. The background material alone will provide an important resource in this field.

With that background, let me now turn to the five issues central to the Taskforce recommendations that I foreshadowed earlier, starting with a definition of an electronic health record.

Issue 1: What is an electronic health record?

I have been talking to you about electronic health records. And there is a considerable body of work on the topic as you are well aware. But what do we mean by the term?

Probably a good starting point is to think about the properties or characteristics of electronic health records. The elements people are looking for include:

- individual, consumer-centric focus;
- flexibility;
- availability and timeliness — for clinical decision-support;
- applicability for population studies;
- guaranteed confidentiality; and
- secure storage and transmittal.

With these 'properties' in mind, the Taskforce has proposed the following definition:

An electronic health record is 'an electronic longitudinal collection of personal health information, usually based on the individual, entered or accepted by health care providers, which can be distributed over a number of sites or aggregated at a particular source. The information is organised primarily to support continuing,

efficient and quality health care. The record is under the control of the consumer and is to be stored and transmitted securely.'

Issue 2: A national approach - the evidence and objectives

The Taskforce was supported greatly by the work of Dr Sam Heard and his team from Flinders University and overseas. This team was engaged to assess the benefits and difficulties of introducing a national approach to electronic health records for Australians. Specifically, the purpose of their investigation was to examine whether there is sufficient evidence or justification for introducing electronic health records in Australia.

The team presented its findings in the report '*The Benefits and Difficulties of Introducing a National Approach to Electronic Health Records in Australia*'. This paper is included in the Taskforce report. In it, the team supports the adoption of a national approach for Australia.

The Taskforce has been able to summarise these benefits which include:

- empowering consumers;
- reducing the number of medical misadventures and dangerous drug interactions;
- providing a personalised medical alert system;
- building a better evidence base;
- enhancing the privacy and confidentiality of people's health information;
- improving coordination of care;
- ensuring important details from a person's medical history are available when it is most needed;
- reducing unnecessary repetition of tests; and
- enabling governments to make better decisions about health areas that should be targeted.

The Flinders University report also discussed the difficulties of implementing a national approach to electronic health records. The major difficulties are seen to be:

- the need for standardised clinical terminology;
- concerns about data privacy, confidentiality and security;
- challenges of data entry by health providers; and
- difficulties of integration of electronic health records with other sources of information in health care settings.

The need for a national approach to electronic health records

The emphasis of the Sam Heard study was on the need for a **national approach** rather than just on whether electronic records can provide benefits. The question of a national approach is extremely important to the work and recommendations of the Taskforce – I will take you through this issue now.

The need for a national approach can best be understood by contemplating the opposite — that is, a scenario in which there is no national leadership, and the States and Territories and the private sector each go their own way. What is likely to happen in this environment is that different approaches would be adopted in different jurisdictions or in different hospitals or health regions. In the private sector, general practitioners are likely to be signed up by vendors with particular solutions, some of them proprietary. Health information would break down into smaller networks – isolating some jurisdictions, individual organisations such as hospitals, or even individual health providers including general practitioners. Standards in terms of what information is collected and how it is recorded, stored and used, would not be established or maintained at a national level.

The consequences are likely to include wasteful investment in some systems that will prove to be unsatisfactory – with no more rapid development than now. Even where systems prove useful at a local level, the lack of a national approach will restrict the range of information transfer to regional or state borders. This will compromise the ability to develop a national picture of our health system.

A national approach is designed to create greater coherence, establish national standards and provide a framework for compatible systems across the nation — so that information can be exchanged at a clinical level no matter what state or regional borders are being crossed. Investment should also be more secure as vendors and purchasers of information systems will know what the rules are and that the systems on offer comply with the rules.

As a simple example consider the case of a woman aged 52 who has had chronic health problems for many years. She has also moved several times – including interstate. She has had numerous treatments and tests, and finds it difficult to recall all the details each time she sees a new general practitioner or specialist. *HealthConnect* will solve this problem. By giving permission for her health care provider to access her medical history, any new provider will be able to treat the woman informed by her complete health history.

The need for a national approach is accepted and supported, I believe, by the vast majority of people in this room. The national *Health Online* strategy advocates a national approach and the National Electronic Health Records Taskforce was established with this as its premise.

Objectives for a national approach to electronic health records

Convinced of the necessity of a national approach, the Taskforce turned its attention to the desired objectives of a system of electronic health records scheme.

After some consideration and considerable contributions from the public submission process, Taskforce members agreed on an objectives statement, as follows:

Improved delivery of health care and better quality of care, consumer safety and health outcomes for all Australians while enhancing privacy and respecting the dignity of health consumers by:

- empowering consumers;
- ensuring better decision-making;
- providing a flexible, seamless and integrated process of care;
- providing better access to health care;
- building a best-practice evidence based health system;
- encouraging better, more targeted health initiatives; and
- informing research, learning and training,

through developing a nationally coordinated and distributed system of electronic health records , which is based on the greater use of online technologies.

The first part is an overarching statement. This incorporates the idea of improving delivery of health care and quality of care, consumer safety and health outcomes, while enhancing the privacy and respecting the dignity of health consumers. This dual theme of improving care and enhancing privacy occurs throughout the report.

The second part of the objective statement identifies some of the activities that will contribute towards the overall aim. The third part broadly outlines the means of realising these improvements.

Issue 3: how to progress a national approach – four options

In looking at possible approaches, the Taskforce considered four options:

- establishing the necessary standards only and letting the marketplace develop the tools and products;
- focusing on the development of record systems within health care institutions and encouraging communications between them;
- building a comprehensive national, electronic health record system; and
- creating a national network for collecting, storing and sharing information in a flexible way.

The Taskforce concluded that options one and two were necessary stepping stones but insufficient in themselves to meet the desired objectives. There is a risk that data would remain fragmented even if in electronic form. There is also a concern that scarce resources could be wasted through duplicated effort.

Option three represents a highly centralised and rigid approach. Stakeholders expressed concern about the possibility of a comprehensive, single electronic record – from the point of view of its practicality, as well as its privacy implications.

Option four, a national health information network, meets our objectives. While it is a major undertaking, the Taskforce considered it achievable and of considerable benefit to the nation's health. It is also consistent with stakeholder feedback in that it provides an

approach that is flexible, can be added to over time and can be useful to all the major stakeholders.

Issue 4: the preferred option – HealthConnect: A National Health Information Network

What we have proposed and Health Ministers have endorsed is *HealthConnect*: the building of a national health information network which provides for the systematic collection of personal health information at the point of care, with consumer permission, and the means for secure, online collection, storage and exchange of health information.

The major components of *HealthConnect* are:

- event summaries;
- online storage nodes;
- central services;
- applications; and
- access points.

A fundamental principle of *HealthConnect* is that all personal health information originates with the consumer and that that information is maintained within a rigorous privacy framework — unless we get the privacy issues right, consumers and providers simply won't use the network.

The source systems are information systems used by participating providers and consumers. These systems will be capable of preparing and issuing event summaries in accordance with the agreed standards for their structure and content.

Event summaries are standardised reports containing key information describing the relevant health episode. These will usually be produced automatically from information collected by providers for their own purposes.

The *online storage nodes* are simply computers that will store the event summaries in a fashion that enables ready access to and use of the data they contain. To satisfy this requirement they will need to conform to an agreed structure.

To operate efficiently, the network will require a number of *central services*. Foremost among these will be an index listing the location of all the event summaries. This index will allow the system to rapidly locate any desired information when preparing reports for users. Other services could include identification, communications, and offline analytical capability.

Applications will be computer programs that allow network users to view the information in ways that meet their particular needs. Examples would include an emergency record, a health summary tailored to the particular needs of the user, medication lists and pathology results.

Access points will be provided by secure Internet connections. For providers these will be at the point of care. For consumers, this could be from home or public access points. At some point consumers may also elect to construct their own health histories and store them on personalised Web pages. However, where people choose not to access their own health information directly, ready access to paper copies will be required. For other users, access would be provided by desktop Internet connections that form part of the network.

How will the network be managed? The Taskforce recognised that *HealthConnect* will need a governance body that can ensure that the operation of the network conforms to agreed protocols. There is continuing debate about the structure of the governance body. It is clear that there needs to be a distinction between operational aspects such as managing the construction of the network and operating it on a day-to-day basis, and controlling access to the network.

It is also clear that *HealthConnect* cannot operate effectively unless important infrastructure elements or ‘building blocks’ are in place.

Issue 5: where next? the building blocks and beyond

The building blocks of a national information health network have emerged as a major theme in both the public consultation process and in the work done by the Taskforce. These represent the pivotal concerns identified by both the Taskforce and stakeholder groups as needing to be addressed *before* a national approach to an electronic health records system can be implemented.

These building blocks include:

- privacy, confidentiality and security;
- standards;
- telecommunications infrastructure; and
- the use of information and communication technologies by providers.

I would like to reflect briefly on each of these, as a national approach to electronic health records will only be possible when they have been satisfactorily addressed.

Privacy

Privacy is a primary concern in the Taskforce recommendations. There was a clear expectation that there were opportunities to improve the current situation regarding the privacy of personal health information — while recognising there are risks that will need to be managed, especially as the new system would involve a health identifier and the collection of very sensitive information.

Several issues are involved. Clearly, personal health information should be kept confidential – it should be used only for approved purposes and shared only among authorised people. However, privacy is also about individuals knowing *why* information

is collected about them, *who* has access to their information, *how* it will be used and by whom.

At a minimum, any approach to protecting privacy in the context of electronic health records must be based on the following premises:

- participation by consumers (and providers) must be based on informed consent;
- an appropriate legislative framework needs to be in place, that:
 - provides complaints mechanisms and rights of redress;
 - holds liable individuals who misuse such information;
 - individuals' health information should be only used and disclosed for health sector purposes;
 - consumers should have access to their own health information and control over who has access to their information and to whom it is disclosed;
 - appropriate security measures must be in place wherever health information is collected, stored or transmitted; and
 - any secondary uses of health consumers' information such as for research, policy or planning, must pass the test that they are in the public interest and that personal privacy is not compromised.

Work has begun on the immediate task of developing the privacy infrastructure. A working group with government, provider and consumer representation has been established to develop a national legislative framework for health information privacy. The aim is to create a health privacy code that would bind providers and organisations that use the network.

The group will be consulting widely. While the desired outcome will not be easily achieved, there is a strong commitment from all the participants to ensure the group is successful and Ministers have asked for a report on the code before the end of the year.

Security and authentication

Security is a high priority. In any system of electronic health records, adequate administrative and technical measures must safeguard health records against loss, modification and inappropriate disclosure.

Accurately identifying people is an essential safety measure to ensure that the correct information is used to make clinical decisions. This will require the use of an identifying mechanism. Equally, it is necessary to accurately identify providers to ensure that they are only supplied with the information that they are authorised to receive by the consumer. The Taskforce has recommended the establishment of a national identifier to be used only within the health sector. Provider and facility identifiers were also seen as an essential element of the security framework.

The use of encryption technology supported by Public Key Infrastructure will be an important mechanism to ensure the security of information during exchange. Public Key Infrastructure provides the structures necessary for the safe issue and use of public and

private encryption keys. Other mechanisms are required to keep stored information secure.

Standards

The use of electronic health records to date has been hampered by a lack of widely agreed and implemented standards for health information. Until health care providers collect data in a standard format according to widely accepted definitions, it will be impossible to link information generated in different parts of the health system in any meaningful way – or to provide any reliable system of health records.

The required standards therefore concern data definitions, coding and messaging. In this regard the Taskforce has been fortunate in having a parallel process of standards development agreed by NHIMAC. A draft *National Standards Plan for Australia* has been developed and will provide a ready-made vehicle to encompass the standards development work required by electronic health records.

For a moment, though, I would like to dwell on information storage. This goes to the heart of the options for electronic health records I have spoken about. If there were no storage or no standard storage facilities where information could be deposited and retrieved, the system of electronic records would always be limited – and is unlikely to achieve the objectives developed by the Taskforce. On the other hand, if we choose to develop a standard for information storage, there are some options available to us – the most promising of which is the Good Electronic Health Record or GEHR being trialed by the General Practice Computing Group. The Taskforce has advocated further investigation of storage standards before any final decisions are taken, and will be watching the GPCG trial closely to help inform the process.

Telecommunications infrastructure

The third of the so-called ‘building blocks’ I want to mention is the telecommunications infrastructure. We do, of course, live in a de-regulated telecommunications market and also one that, on the whole, provides a solid backbone for collecting, storing and exchanging electronic health information.

The Taskforce has taken the view that the approach it is recommending should be Internet-based and rely on the general telecommunications environment. Having said this, however, the Taskforce also considers it is important to both plan and support the development of the telecommunications services that electronic health systems need, as well as look at the steps required to build links between health care providers on a regional, state and national level. That is, we need a considered, strategic approach to telecommunications services for health.

Use of information technology by providers

Another building block that needs to be developed is the uptake of information and communication technologies by health care providers and organisations. While a lot of work is being done in this area in many sectors, particularly public hospitals, community care and general practice, more is required in other areas such as specialist medicine.

Lead implementation site(s)

Once work on the building blocks is sufficiently advanced, development of the lead implementation site or sites can commence. This will be the first major area of work directly related to the network.

Notwithstanding the lessons that can be learnt from existing initiatives, the Taskforce believes that it will be necessary to establish one (or more) lead implementation site(s) to implement various aspects of the network in microcosm (including, desirably, a mini version of the full Network). Such a site would prove the concepts and technical feasibility of the Network and the building blocks that support it in an experimental environment that can be closely monitored, managed and learnt from.

Better Medication Management System

Finally, I would like to briefly mention one initiative that is currently underway and highly pertinent to the work of the Taskforce.

The Better Medication Management System (BMMS), which was announced in this year's Federal Budget, is being developed in parallel with the work of the Electronic Health Records Taskforce. The essential features of the BMMS were initially proposed to the Government by a group of consumer, pharmacy and medical representatives. An expanded BMMS Development Group, incorporating a broader spectrum of Australian community interests, is currently engaged in further developing the BMMS through to its implementation on 1 July 2001.

The BMMS is based on creating an individual electronic patient medication record that will link prescriptions written by different doctors or dispensed by different pharmacists. Voluntary participation by consumers, prescribers and dispensers is fundamental to the concept. This new system has the potential to assist in achieving significantly better health outcomes for all Australians by influencing the environment in which prescribing decisions are made, and by promoting informed medication management partnerships between consumers and their doctors and pharmacists. It offers us the chance, in a much more limited context, to explore some of the issues around the electronic health record initiative and to glean important insights along the way.

Professor Michael Kidd, who is a member of the BMMS Development Group, and Ms Rachel Stephen-Smith, who is a member of the Development Group's Privacy Working Group, will be speaking to us about the BMMS after lunch in the Clinical Information Systems session.

Conclusion

The road ahead for the development of a national approach to electronic health records is long and winding. It will be littered with obstacles. Many issues still need to be teased out and discussed, and much work needs to be done in establishing a consistent approach to

be pursued. The key stakeholder groups, particularly consumers and providers, will need to be directly involved in the processes that follow the recent decision of Health Ministers to endorse fully the report of the National Electronic Health Records Taskforce.

However, Ministers want us to work quickly to achieve early returns, demonstrate the value of the network, reach an agreed privacy framework, firm up on network costing and build the other network infrastructure.

In terms of setting a national agenda, I think that we have made a great start with the work of the Taskforce and other groups and individuals who have played a part in informing the debate so far. Although the issues we are dealing with are dauntingly complex, I am excited to be involved in this process. It provides the opportunity to work with diverse groups to achieve a common goal, which in the long run will provide better outcomes for consumers and better support for health care providers.

I look forward to the work ahead, and firmly believe that the careful thought and tireless work being invested in this process will result in an approach to electronic health records that will deliver the best possible system for consumers and providers alike.

CLINICAL INFORMATION SYSTEMS – WHAT’S NEW AND INNOVATIVE?

NSW Health clinical initiatives

Ms Dianne Ayres

Manager, Clinical Systems, NSW Health

NSW Health has a number of clinical initiatives in various stages of implementation. The following programs are the subject of this brief overview:

- Point-of-Care Clinical Systems
- Electronic Prescribing
- Clinical Information Access Program
- Collaborative Research Projects
- GP Information Management and Technology Strategy

Point-of-Care Clinical Systems

A Point of Care Clinical System (PoCCS) is the core information technology infrastructure that captures information generated by a doctor, nurse or allied health professional (clinician) to document the care process. This may be in a hospital ward, outpatient clinic, emergency department or health professional’s office. A point-of-care clinical system (PoCCS) enables the clinician to:

- record care where and when it is delivered
- review progress and order treatment or tests from any location where a computer is located
- continually review results and outcomes and alter care as required
- be prompted with alerts and allergies at time of ordering
- generate a clinical pathway or care plan to prescribe care for the patient's length of stay in hospital
- monitor progress on the clinical pathway and record variances to analyse outcomes
- utilise decision support at the time of ordering and on review of clinical outcomes
- measure patient acuity to determine the intensity and complexity of care required and given
- generate discharge referrals with automatic feeds from relevant systems eg. radiology, pathology

Modules of a Point-of-Care System

A PoCCS comprises a number of modules including;

- Results Reports
- Order Management
 - Rules Engine

- Clinical Documentation
 - Structured Notes
 - Clinical Pathways/Care Plans
 - Charting
 - Medical Alerts
 - Acuity
 - Variance Reports
 - Discharge Referrals
 - Clinical Protocols

In October 1999, NSW Health distributed a Request for Information for a Point-of-Care Clinical System, which has resulted in four applications being short-listed for a selective tender. The tender will be distributed in early September 2000.

The Point-of-Care Clinical Systems initiative and new Patient Administration Systems are now a priority program under the NSW Government's Action Plan for Health, which recommended that patient care systems in the hospitals needed to be improved. IT initiatives have been prioritised to focus on:

- supporting clinical practice with PAS and PoCCS
- linking GPs, community health and hospital information to access discharge referrals, results reports and other event information
- promoting consumer participation
- establishing an Electronic Health Record (EHR) by 2010

NSW Health has established a number of working groups to progress all priority initiatives.

Electronic Prescription Decision Support Systems

A project is currently in progress to develop functional requirements and subsequently seek solutions for an electronic prescription decision support system (E-PDS). The aim is to improve the quality and safety of patient care by:

- Improving prescribing practices and medication management.
- Reducing the number of Adverse Drug Events (ADEs).
- Decreasing the number of complications due to ADEs.
- Reducing the cost of health care by reducing inappropriate prescribing.
- Reducing Length of Stay (LOS) by reducing ADEs through improved and appropriate prescribing management.
- Improving staff and consumer knowledge about drugs and drug interactions.

E-PDS systems are complementary to PoCCS and the Clinical Information Access Program (CIAP) and increase the value of clinical information for decision support. E-PDS helps the doctor to prescribe appropriately and be prompted with drug options related to the disease to be treated, dosage by age and weight, contraindications, drug interactions, and costs. It also aids in medication tracking which is useful from the perspective of the pharmacy, clinical unit and doctor's office.

According to the literature, systems that give clinicians immediate and direct feedback during the prescribing process are most effective in changing behaviour and improving quality. Studies have shown that applying computer technology to prescription writing significantly reduces the cost of medications while promoting adherence to protocols. E-PDS systems can deliver both patient care and health care provider benefits and are even more powerful when integrated with order management, pharmacy management and the CIAP. It is anticipated that a Request for Information would be issued in November 2000. A Web site with further information is accessible from the following address: <http://www.clininfo.health.nsw.gov.au/pdsp/pdsp.html>.

Clinical Information Access Program

The Clinical Information Access Program (CIAP) is a web site of clinical information located at <http://www.clininfo.health.nsw.gov.au>. This web site focuses on clinical information to assist clinicians with information to support clinical practice, education and research.

The Key Drivers for the CIAP were to:

- improve access to decision support;
- support evidence based health care;
- reduce adverse events;
- improve clinical knowledge; and
- improve communications between clinician groups.

Information provided on the CIAP includes many drug and reference databases, electronic journals and textbooks. Local information includes policies, protocols, guidelines, research and any other information requested by clinicians as useful to support clinical practice, education and research. It is also the major means of communicating information about IT projects and committees addressing clinical IT issues.

The CIAP is now considered to be an operational system complementary to a point-of-care clinical system and electronic prescribing. It has been a highly successful project that has been widely accepted by all clinician groups. Clinicians believe that this is the most successful project that the Department of Health has ever managed in terms of providing them with information to support clinical practice. An on-line survey demonstrated that 90% of participants believed that access to this information has assisted them to improve patient care.

The CIAP has won two awards and been nominated in the top ten web sites in Australia - a testament to the value of information to support patient care. Anecdotal evidence from a continuous on-line survey has identified that there are many instances where access to information has saved lives and changed the course of treatment for patients, with positive outcomes.

Because of the interest from clinicians in other Australian Government Departments a GITC contract was established. This enables any government department to buy services and information resources without having to tender. A Consortium arrangement brings economies of scale when purchasing information resources. The Health Departments of WA, SA, Queensland and Victoria are now members of the Consortium.

A National User Group forum is planned for 26 October 2000. This will bring together program managers and CIAP representatives from around the country to provide a forum for exchange of ideas and innovations and to look at areas where web based information resources may need to be improved to be 'clinician friendly'.

The objectives of the National Forum are to:

- provide a mechanism for generating and sharing information
- to examine the impact of information technology in areas of clinical practice
- to provide an update on trends, developments and innovations in Australian sites which have adopted web based clinical information resources for clinicians

Invitations will be distributed to all member States of the Consortium and to Australian State Health Departments that have not yet joined the Consortium.

Research

The CIAP has provided many opportunities for research. The NSW Health Collaborative Projects Planning Committee (CPPC) has defined a series of research projects to be conducted over the next two years to evaluate the effectiveness of the CIAP. Several PhD students are using this program as the basis of their research. This research may also provide opportunities for collaborative research nationally. The CPPC research projects are:

Project 1: analysis of web usage logs

AIM: to review and analyze data available for CIAP web usage to inform the managerial, educational, marketing and technical development of CIAP.

Project 2: assessing factors influencing variation in uptake And utilisation

AIM: to identify human and organizational factors related to adoption of CIAP

Project 3: usability testing of CIAP interface

AIM: to identify and assess usability features of the CIAP interface.

Project 4: investigation of value of investments in CIAP

AIM: to ascertain financial and non-financial value of using CIAP at local level.

Project 5: design and conduct of CIAP impact evaluation

AIM: to design and implement impact evaluation of CIAP on clinical processes and outcomes

Communications research

A 1999 Emergency Department communication study by the CPPC led to the development of a proposal to design a comprehensive evaluation of communication systems in the NSW Health System in 2000/1. The projects will develop and disseminate the communication behaviour study methodology successfully piloted in the earlier study, as well as extend the data collection and analysis to other sectors of the health system. This effectively builds on the earlier project to develop a strong skill set for the sustainable evaluation and improvement of communication systems within the NSW health sector.

Project 1

AIM: The project will result in more detailed analysis of the data collected from the original research, as well as an extension of the data gathering. The original study broadly grouped the interactions of medical and nursing personnel in the clinical setting. This proposal will more clearly identify the factors affecting a professional's choice of communication about clinical issues. Armed with this knowledge, the most effective use of information technology can be identified and effort channeled to developing clinical systems tailored to clinician's preferred processes.

Project 2

Aims: Project 2 seeks to refine, document and disseminate the observational tools and measures used in the original project. These tools can then be used more widely by NSW Health to measure communication processes in clinical settings and assessing the benefits and impact of the use of the developed methodology in these settings. This refinement will also improve the efficiency of the data collection and analysis processes, which are currently time consuming. The project leverages investment in existing methodology and allows transfer to other NSW institutions and researchers.

Project 3

Aims: Based upon the user needs identified within project 1 and earlier studies, we would like to build and test specific communication services on new classes of palm-top devices. Communication difficulties are related to poor support for interaction amongst clinical teams, and with the current generation of mobile communication devices we are at last in a position to develop health-specific systems to support clinicians. For example, distributed members of a clinical team can have enhanced communication by all accessing shared task lists and diaries whilst they are mobile. This project will introduce

and then evaluate the impact of such an intervention. The newly formed Informatics Evaluation Group at CHI will support the evaluation with advice and in-kind contributions.

The above research projects are funded by NSW Health and conducted by the University of New South Wales on behalf of the CPPC which has representation from all Universities in New South Wales that have faculties of Nursing, Medicine and Allied Health. NSW Health and the CPPC will be looking for opportunities to collaborate on research across the Nation.

GP strategy

The NSW GP IM&T Strategy (1998) described the specific information management reforms required for a partnership relationship between the public health sector and General Practice. The six key goals of the Strategy are to:

- Increase cooperation between key players
- Increase GP awareness of IM&T
- Improve computing skills in general practice and Divisions of General Practice
- Improve the risk environment of GP IM&T
- Improve communications and sharing of patient clinical data including electronic data transfer
- Improve GP access to electronic decision support tools.

Priority projects under the Strategy include patient event notification, emergency department reporting, access to results reporting and discharge referral. All must be underpinned by substantial work practice changes.

Attention to information exchange between NSW GPs and Area Health Services has highlighted the resource and infrastructure pre-requisites for change as well as the additional system refinements needed to comply with security and privacy responsibilities. State and Commonwealth funds will be available in 2000/01 to contribute to Area initiatives. As importantly, the Government's Action Plan for Health, addressing the recommendations of the NSW Health Council, has provided critical impetus to implementation of the Strategy. In essence the Report prioritised the efficient exchange of clinical information between health professionals as a basis for improved patient care, explicitly including general practitioners within the communication network.

Conclusion

Within the framework of the NSW Government's Action Plan for Health, a number of Information Technology initiatives have been given a high priority with the aim of supporting clinical practice across the continuum of care, engaging consumers, improving integration and access to information and establishing a framework for the Electronic Health Record. Underpinning all of these initiatives is an information management and technology and telecommunications strategy, data and security standards and a privacy framework. Evaluation is a key aspect of implementing any IT initiative, hence the

reason for the numerous research programs being undertaken by the CPPC. The clinical initiatives addressed in this overview are some of the key programs that will have an impact on the safety and quality of patient care in NSW Health facilities.

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A consumer perspective on the Better Medication Management System

*Ms Rachel Stephen-Smith
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Thank you Tom. Like Professor Kidd, I'm here today to talk about the Better Medication Management System, or BMMS. Unlike Michael, however, I'm here to talk about it from a consumer perspective.

In that context, a lot of what I say will not be specific to the BMMS. I'm going to talk about some of the fundamentals that need to be addressed in order for *any* electronic health records system to be accepted by consumers. I will then look particularly at the issues of privacy and consumers' control over their records and some elements of how these issues are being addressed in developing the BMMS.

Benefits

To start with though, I think it is important to recognise that many consumers do see the potential benefits of electronic medication records. It is a fact that many consumers, particularly those with chronic illness, currently face a fragmented system which often requires them to take sole responsibility for keeping track of their medications, visits to doctors, etc – while at the same time the consumers themselves lack any real empowerment or control over what happens to them. Electronic records have the potential to improve this situation.

I'd like to quote a bit from a recent article in *Health Issues* about developing partnerships between health care professionals and people with chronic illness, in which the issue of smart cards and electronic records was briefly discussed.¹ The article began:

A few years ago members of the Chronic Illness Alliance were discussing the costs of pharmaceuticals when they moved on to the topic of smart cards, electronic records, and so on. Surprisingly, most of those present were strongly in favour of electronic records and of electronic records of medication. They argued that when a person has a chronic illness, they have a long history of treatments and medications and there were many occasions for confusion and mishap over both of these.

Of course, this article does go on to sound a note of caution and I'm hoping that now that I've talked about the benefits I can also safely return to the cautionary side of things without being branded a wet blanket. Because the fact is that many consumers see, and

¹ Walker, Christine, 'Partnerships between Health Care Professionals and People with Chronic Illness', *Health Issues*, Vol. 63, June 2000, Health Issues Centre

experience has shown that there are, some risks involved in the implementation of electronic health record systems.

Objectives

The first thing I see as necessary in minimising these risks is starting out with the right objective. In the Consumers' Health Forum's view, the objective must be, and must be strongly seen to be, improved health outcomes for the individuals who choose to participate. Consumers will be suspicious, and rightly so, of any system which has as its objective cost savings or administrative efficiency. The experience of the National Health Service in the United Kingdom clearly shows that systems implemented primarily with cost and efficiency objectives in mind lend themselves to both privacy and safety failures.² Thankfully, Australian policy makers appear to agree with the objective being better health outcomes for consumers.

Fundamentals

Once the objective has been established there are a number of fundamentals that need to be in place for an electronic records system to operate successfully. If these fundamentals are not addressed, consumers and providers alike will be unwilling to participate in the system and that, in itself, will prevent it from achieving its objective.

Consumer consultations have identified these fundamentals as:

- a strong and effective legislative framework to protect consumer privacy;
- a voluntary system;
- consumer control over who has access to their records;
- consumers' access to their own records;
- accountability in the overall governance of the system;
- effective enforcement mechanisms, including an accessible complaints mechanism, an independent body which can initiate investigations into serious or systemic breaches, and enforceable sanctions imposed on those who abuse the system; and
- the availability of comprehensive information for consumers about what the system is, how it works, how it may benefit them and what they can do to get the best out of it.

Privacy

Many of these fundamentals relate directly to reassuring consumers that their privacy will be protected and I would just like to talk briefly about why this is so important.

While it is easy to dismiss privacy concerns as paranoia on the part of a small group of consumers, that really is a simplistic view, and certainly not helpful – especially as broad

² Anderson, Ross J, 'Information technology in medical practice: safety and privacy lessons from the united Kingdom', <http://www.cl.cam.ac.uk/users/rja14/austmedjour/austmedjour.html>, November 1998, subsequently appearing in the Australian Medical Journal

consumer consultations have consistently identified privacy as being of the utmost importance.

To return to the article in *Health Issues*, which I quoted from earlier, it went on to say in the context of smart cards that:

Amongst this group [of people with chronic illness] there was a great awareness of the needs for privacy and confidentiality; possibly no other group is more aware of their needs in this area around insurance, superannuation and workplace relations. These needs were outstripped by the great advantages to be achieved through having a life time record ... It is worth noting however, that all those present agreed that they would only contemplate such a record if they could hold the card themselves and could access its information.

As the quote indicates, consumers see having control over their own records as an important way of addressing their need for privacy, and that's what most of the rest of my talk will be about. First, however, I'll just touch on the need for strong legislation to provide a framework on which we can build these specific protections.

Legislation

At the moment, the privacy of health information is partially protected by a patchwork of Commonwealth and State legislation. The level of protection under legislation and regulations varies considerably – from very good for MBS and PBS data to non-existent for most information held in the private sector outside the ACT or NSW private hospitals.

You are probably aware that there is currently a Bill in the Parliament called the *Privacy Amendment (Private Sector) Bill*. This is often cited in e-health proposals as being a first step to strong privacy protection. In fact, in the Consumers' Health Forum's view, the Bill would do very little in its current form to protect the privacy of consumers' health information.³

In the context of the BMMS, therefore, we are pleased that the need for separate legislation has been recognised by both the development group and the Minister. Dr Wooldridge has said that such legislation will have to be passed by Parliament and come into force before the BMMS comes into operation. This legislation is currently being developed in consultation with the relevant stakeholders, including consumers.

³ CHF, *Submission to the House of Representatives Standing Committee on Legal and Constitutional Affairs Inquiry into the Privacy Amendment (Private Sector) Bill 2000*, 15 May 2000, <http://www.chf.org.au>

Voluntary nature

Once legislation is in place, the voluntary nature of the system and consumer control over who has access to their health records become key factors in protecting consumers' privacy.

The Minister has emphasised the voluntary nature of any electronic health records system that is to be introduced in Australia. In practical terms, this means that consumers must choose to 'opt in' to the system on the basis of full information. Making this work will require comprehensive information to be provided for consumers through a range of sources, including consumer organisations, professional groups, individual practitioners and the media. A particular aim would be to target those who will benefit most from the BMMS and ensure that their concerns have been addressed.

Control

Once they have opted in, consumers must be able to choose which providers can access their records, and when, and be able to monitor access. They must also have the right to suppress certain parts of their record. These requirements have both practical and safety implications.

Consent

Deciding which providers can access a consumer's record after they've opted in requires some sort of consent mechanism. The current proposal is that consumers will have to give consent each time the record is accessed and must be present when a provider is accessing their record. This leads to practical questions about what kind of technology is going to be acceptable, both to consumers and to health professionals, and how cumbersome the process will be. These questions have yet to be answered in the context of the BMMS, but work is under way to look at the impact of various options on the ground.

Audit trail

In order to be sure that their records are properly protected, consumers will need to be able to track who has accessed their record. To implement this, it is envisaged that the 'consumer view' of the BMMS record will include an audit trail. This 'consumer view' will be protected from access by providers, presumably by a password or the like, and the audit trail will allow consumers to ensure that their information has only been accessed by those to whom they have given consent.

Of course, it should be noted that consumers' access to their own health information provides benefits far beyond auditing. Access in and of itself will help to improve health

outcomes through increasing consumer empowerment and contributing to more informed decision-making.

Suppression

Probably the most contentious issue relating to consumer control is that of suppression – that is, a consumer’s right to suppress a particular prescription and dispensing event, so that the only providers who can view that information are those who wrote the prescription and dispensed the medication. Suppression is an issue on which there is ongoing discussion.

Some stakeholders have raised safety issues, questioning the value of the medication record if it is not complete. Some have suggested that the record should be flagged to indicate a suppressed medication. But if the record were flagged to show that a medication has been suppressed, what would that mean? The probability is that the stigma would remain. So the alternative for the consumer would be to stop the information they want protected from being entered in the first place by opting out of the system for that particular encounter. This would be no better for other doctors, in terms of completeness of the record, and probably worse for the consumer and the prescriber.

It is interesting to note that the consumer groups who were most concerned to ensure that a record could be suppressed did recognise the risks involved. However, they noted that they would be likely to consult the prescriber of the suppressed medication if they were concerned about possible adverse interactions with a new medication prescribed by someone else. For example, someone with a mental illness may ring his or her psychiatrist for advice, while someone with a sexually transmitted disease may consult the STD clinic.

In order to minimise the risk, however, CHF considers that those prescribers whose prescriptions are suppressed should have a responsibility to provide the consumer with comprehensive medicines information in a language that they can understand. For example, “this drug I’ve just prescribed for you cannot be taken with some medications for treating high blood pressure. If you see another doctor for high blood pressure, I advise you to let them know that you are on this drug, or to check with me before taking any other drug they prescribe.”

Finally, as one of the pharmacists’ representatives pointed out, it is important to remember that no doctor will ever be able to assume a record is complete. The consumer may have visited a doctor or pharmacist who didn’t participate in the system. They may have got confused when asked by another doctor whether they participated, said no and therefore didn’t have that information recorded. Or they may have only just opted in but still be taking medicines not entered in the system, or have a history of adverse reaction which is not recorded. Any way you look at, you can never assume the record is 100 per cent complete.

Conclusion

This observation highlights a very important point and I think, therefore, is a fitting note for me to end on. So I'll leave you with a reminder that the BMMS, or any other electronic records system, can never replace good communication between health professionals and consumers. Rather, we should view accessible, consumer controlled and user-friendly electronic records as a basis for more open communication between health professionals and consumers and better informed, shared decision-making.

The electronic medical record via a flexible, scalable, low cost, distributed information architecture

Dr David Woodcock

Peter MacCallum Cancer Institute, Melbourne, and Verinet Solutions

Summary

The 'Patient Browser' is an Electronic Medical Record/Clinical Viewer system developed initially for in-house use at the Peter MacCallum Cancer Institute, Melbourne. This is a web browser-based system that presents a unified interface to all the diverse data systems within the Institute and has been in practical clinical use there for more than two years. It can form the basis for a much broader system for controlled access to clinical information.

The problem

Clinical data resides in many and varied forms within even a single health care institution. To provide a single electronic interface for the presentation of these diverse data sets, the conventional solution has required:

1. Messaging between departmental systems (eg. Patient Master Index, pharmacy, pathology, radiology, etc) with some form of 'integration engine' that can transform these data into a manageable form. This is where the HL7 standards play an important role.
2. These data are stored in a large central database that must be big enough to keep sufficient of the information held in the several feeder systems in enough depth and for a long enough time that users do not have to go back to these systems for information needed in patient treatment.
3. An application to provide structured access to the information residing in the clinical repository.
4. High-end computer hardware to run the central database and the clinical viewer application.
5. Hardware to run the integration engine.

The Peter Mac/Verinet solution

The essential elements are:

1. A web server that is also running a business object written in Visual Basic 6.
2. Directly access information in the departmental systems using computer industry standard interfaces (ODBC, OLE DB, XML) from this business object.
3. Use a web browser⁴ as a container to display the information.

⁴ Why a web browser? The simple answer is that a web browser is very adept at displaying a broad range of content types and, at least for the Microsoft product, is free for business use.

4. The only hardware is a clone PC running Windows NT.

Items no longer required:

1. The large central database.
2. The integration engine.
3. The hardware required to run the integration engine, the large central database, and the clinical viewer application running off that database.
4. Setting up and reconciling the different versions of HL7 messaging protocols.

Features of the patient browser

1. Granular security. Access to every button and tab can be assigned in any combination for any individual user (Figure 3).
2. Individually assigned inactivity timeouts.
3. Full audit trail running in the background.
4. Need-to-know control of access to clinical data (eg. GPs can search by name only (not by UR number or by ward lists) and then can only see records for patients for whom they are registered as the local or referring practitioner).

Information accessible under the patient browser

We divide information into the following four classes, each of which require different management, but where all can be displayed under the single web browser interface.

1. Data already residing in databases (irrespective of the database type or the operating system on the computer running the application).
2. Locally generated documents that are captured at source and stored in electronic form rather than just being transferred to paper.
3. 'Inevitable' paper: the backlog of the old paper record plus letters and test results coming from external practitioners.
4. Medical images.

Examples of information displayed under the patient browser

The most sections of the clinical information most highly used by clinical users are (in descending order), pathology, radiology, and clinical notes.

Overall characteristics

The Patient Browser has a graphical interface (GUI) and is highly intuitive for those used to using Windows programs. Training sessions for new staff lasts for no more than 30 minutes. There is a maximum of 3 clicks for any information to be retrieved.

In addition, the architecture of the whole system is very 'modular'. Not only can new software components for the system be 'plugged in' to augment or replace existing modules, departmental feeder systems can be replaced from under it with minimal loss of

connectivity to these data and with users being unaware of the replacement of the underlying system.

Working with other systems

A button can be added to the Patient Browser that activates another web-based application, with user credentials and patient identifiers being passed during this process. This could be used to activate a PBS prescribing and decision support module, a module for on-line ordering of pathology tests or the viewer module for a full radiology PACS system. To the end-user, this would appear as though they were dealing with a single application where, in fact, they were using a number of separate systems functioning seamlessly together.

Automated discharge information

Since we have links into all the departmental systems via ODBC, OLE DB, or XML, it is a simple matter to compile a 'report' from multiple systems, containing information on the latest episode of care for any recently discharged patient. An admission or discharge can be used as an automatic trigger to generate such a 'report'. Instead of being sent to the screen as in the Patient Browser, it is a simple matter to send it to a printer or fax queue, or as an attachment to an e-mail message, directed to those medical practitioners who are registered as the local or referring doctors.

Secure remote access via Internet

As described above, we have the ability to permit external practitioners to access the information on their own patients (and only their own patients). We ran a small pilot program providing access to external GPs using dial-up (with dial back for security, in addition to the normal security measures). This convinced us that, if this were to be extended to larger numbers of external practitioners, the only feasible way was to do it via the Internet rather than having to set up dial-in accounts and configure computers in general practitioners' offices.

However, we were not prepared to base access to confidential patient information on log-ons or passwords that could be passed on to others. We have recently implemented a multi-layered model for secure access from the Internet using:

1. Hardware-based one-time password generators.
2. RADIUS authentication server.
3. A hardware plus software solution for a triple DES encrypted secure communication channel across the Internet.

This final layer also allows us to control what internal resources are accessible to each external user. This system was implemented using standard industry components and can co-exist with other security mechanisms.

Applicability to secure remote access to patient data

For example, the Patient Browser has now also been installed at Box Hill Hospital, several kilometres away from the main Peter MacCallum campus, but connected by a private dedicated wide area network (WAN) implemented by the former Inner and Eastern Healthcare Network. The Box Hill Hospital implementation is more limited than at Peter Mac with main information available being from pathology but does include basic demographic data. However, this data set is likely to be expanded quite soon to include pharmacy, for example.

We now have the possibility that, when a patient is transferred from Box Hill Hospital the Peter Mac (or is being treated for different conditions concurrently), their data could be made available directly on line (ie. a clinician at the Peter Mac could log onto the BHH 'Patient Browser' server and look up information on specific patients from the BHH systems and vice versa).

Before any of this could happen, it is essential that we have a system in place that ensures that such direct enquiries are done with the explicit consent of the patients concerned. One possible way to achieve this would be to issue patients who might fall into this category with a personal identifier card (or use the patient's National Health Identifier card, if and when available). Such a card could be a 'smartcard' with an encrypted identifier stored on it or it could be something akin to a credit card with a machine-readable personal identifier on it. Whatever level of sophistication of the card, the paradigm would be:

1. the patient has to disclose explicitly that they have a record at another hospital;
2. the patient would have to give specific permission for this information to be accessed remotely by providing access to their personal health ID card; and
3. the local medical officer accesses the remote 'Patient Browser' web server at which point they can search only on this personal health ID number.

This personal health ID could be a very long alphanumeric with some form of checksum at the end to ensure it was a valid 'expression' and could be constructed such that it would be extremely difficult if not impossible to construct a random valid number. This long alphanumeric could be stored encrypted on the smartcard, protected by a PIN number kept by the patient. (If it works for credit cards, why not health ID cards?) As for local infrastructure to read these cards, it is possible to obtain smartcards that can be read in standard 3.5" floppy drives. Alternatively, smartcard readers are becoming relatively inexpensive.

In general, the technology behind the Patient Browser could be used as a low cost foundation for retrieval of dispersed medical episode information. At the simplest level, this could be by direct inquiry into remote systems (possibly as outlined above) or, with the addition of a central cross-index of episodes of care and patient demographics (or National Health Identifiers), as the equivalent of a longitudinal record of care but with the

ability to drill down to fine details if required for some specific treatment requirement (eg. some treatments have a maximum lifetime allowable dose).

Incremental approach

Deploying the Patient Browser in any hospital satisfies the immediate needs of local clinical staff for immediate access to total patient information. As this technology spreads, each additional site is a strategic building block for merged patient information on the broader level (state wide or nation wide). However, unlike 'conventional' solutions, this sort of purely web-based approach is not only much less expensive but has immediate pay-offs at every stage. Also with the component nature of the software, it has built in anti-obsolescence.

While it may be heresy to suggest this in the context of a National Electronic Health Record, the single largest pay-off of this approach would probably be with the initial implementation at the local hospital campus level: providing staff throughout the hospital with immediate access to all the data on their own patients.

Further information

<http://www.patientbrowser.com>

TELEHEALTH – BEYOND THE THINK TANK

Telehealth as a Means of Supporting Primary Care

Dr Ilse Blignault

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Most telehealth applications in Australia to date, as elsewhere, have concerned access to tertiary care facilities from peripheral hospitals. This paper considers the application of telehealth within the framework of primary health care.

Primary health care

The Declaration of Alma Ata defined primary health care as:

“... essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process”. (WHO, 1978, p. 15)

Primary health care is based on five principles that together represent a philosophy of health – equity, prevention, appropriate technology, intersectoral action and community participation (Walt & Rifkin, 1990).

Telehealth

Telehealth or telemedicine is essentially a mechanism or tool for health care delivery.

The World Health Organisation (WHO) adopted the following definition:

“... the delivery of health-care services, where distance is a critical factor, by health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, and for the continuing education of health-care providers as well as research and evaluation, all in the interests

of advancing the health of individuals and their communities”. (WHO cited in Wright, 1998, p. 6)

One of the notable early applications of telehealth was a program established in the late 1950s to deliver health care to residents of the Papago Reservation in Arizona (Space Technology Applied to Rural Papago Advanced Health Care or STARPAHC). A van was outfitted as a medical examination room and staffed by two Native American paramedics. It was connected via microwave video and audio transmission to two hospitals. The project, which successfully provided medical care to several sites on the reservation for over 20 years, finally folded due to lack of maintenance funding and system management (Preston, Brown & Hartley, 1992).

The North-West Telemedicine Project, conducted in Queensland in the mid-1980s, also set out specifically to enhance primary care (Watson, 1989). Satellite was used to link Mt Isa Base Hospital with primary care teams in five isolated communities (Normanton, Karumba, Doomadgee, Mornington Island and Burketown) and the Royal Flying Doctor Service. Other links in the network were to Royal Brisbane Hospital, Townsville General Hospital and Cairns Base Hospital. New communication modes introduced included conference-style telephones, facsimile equipment and slow-scan transceivers. Until then the usual means of communication had been by telephone and/or radiotelephone. During the course of the project, the voice-link was used most often, followed by facsimile. Participants reported improved quality of consultation, greater satisfaction with consultative process and increased confidence in the diagnosis. In addition, there was a reduction in patient evacuations (Watson, 1989). Despite these results, and the enthusiasm of the health workers for the new technology, the initiative was not maintained after project funding ceased.

Telehealth has the potential to improve primary care, especially in rural and remote areas, in two ways (Brick, 1997). First, through the application of telehealth an increased percentage of patients can be treated in their local community hospital or health clinic under the supervision of the local doctor, nurse or health worker, with positive implications for continuity of care. Second, for rural and remote health professionals, telehealth can reduce professional isolation, provide direct and indirect continuing education, and increase contact with other health facilities and access to up-to-date research.

Telehealth and primary health care

Of course, primary care (or the first line of care) is only one component of primary health care (McMurray, 1999). As indicated earlier, primary health care is based on five basic principles: equity, prevention, appropriate technology, and intersectoral action and community participation. How well can telehealth meet these principles?

Equity

Equity is the main principle of primary health care, as outlined in the Alma Ata Declaration. In the words of McMurray (1999, p. 24), “Health for all people means equal

opportunities for all people, whether they differ by geography, race, age, gender, language or functional capacity.”

Proponents of telehealth often refer to its capacity to reduce inequalities of access to health services and information, particularly for isolated communities and other under-served populations (e.g. Swanson, 1999). Telehealth provides a means to improve the availability of services by increasing the supply of services and specialised programs such as mental health. It can increase the acceptability of services so that they better meet the special needs of individuals and communities. For example, through a telehealth network a wider choice of service providers can be made available as well as links to culture and gender specific services. Telehealth provides a means to improve geographical accessibility of services, thus reducing the need for patients to travel long distances to receive care. Finally, by reducing travel and other associated costs, telehealth improves the relative affordability of health services.

STARPAHC (Preston, Brown & Hartley, 1992) and the North-West Telemedicine Project (Watson, 1989) were both designed to provide health services to remote indigenous communities who experienced difficulties access health care due to their distance from major population centres. Interestingly, telehealth has developed most rapidly and extensively in countries and regions where distance and geography present barriers to access to health services and governments are strongly committed to reducing inequalities of access. Many countries now recognise the importance of telecommunications for social and economic development (Wright, 1999).

Prevention

Prevention became an important principle of primary health care because of both cost and human concern (Walt & Rifkin, 1990). It implies a shift in emphasis away from large, tertiary institutions and individual, curative care towards community-based health facilities and preventive activities such as health education. There is no technical reason why telehealth cannot be applied for this purpose. In fact, Malaysia's Telemedicine Blueprint, with its focus on wellness and empowerment, is based on using human resources and technologies in just this way (Ministry of Health, 1997). Around the world, the Internet has become a major source of health information. It could be a powerful tool for health promotion.

Appropriate technology

Although telehealth is often seen as 'high-tech' solution, this need not necessarily be so. In Africa and the small island nations of the Pacific, for example, the emphasis is on low-cost telehealth applications. Most are based on POTS (Plain Old Telephone System) or the Internet and make use of store-and-forward technologies rather than live, two-way or multi-point videoconferencing (Allen, 1999).

In an editorial commenting on Watson's (1989) article on the North-West Telemedicine Project, Lazarus and Leeder (1989) questioned the value of such a 'high-tech' approach when basic technologies such as adequate water supply and sewerage disposal and satisfactory housing were still lacking in many remote Aboriginal communities.

In the pursuit of equitable and effective health care, the importance of choosing the right tool for each job cannot be overemphasised. To lease a satellite transponder to solve the health problems of remote Australian communities may prove to be an effective solution, or it may be similar to using a lithotripter to crack a nut. (Lazarus & Leeder, 1989, p. 59) (A lithotripter is an instrument used for crushing stones in the urinary bladder.)

In a wealthy nation like Australia, surely we need to do both – improve basic community infrastructure and access to health care, making use of information and communication technologies for the latter where necessary. In developing countries, where needs are greater and resources more limited, there may be real concerns that, if additional resources were to become available, telehealth might not be the most appropriate use for them. This is an area where cost-effectiveness studies are urgently needed (Wootton, 1997).

Intersectoral collaboration

Many of the telehealth applications in developing countries have been developed in partnership with the International Telecommunication Union Development Bureau and the Midjan Group, a European association that promotes telehealth in developing countries (Wright, 1998). In North America, Nancy Milio and others have demonstrated the value of modern technologies in assisting disadvantaged communities in strengthening community networks and gaining access to mainstream resources (Milio, 1996). Communication of this kind “can also bind people, fostering cohesion through developing common perspectives, finding common interests, and engaging in joint activities toward shared goals. All of this is eventually beneficial to the welfare of individual members of communities and is essential if health professionals are to be effective in working for an environment conducive to health” (McKnight 1992, cited in Milio, 1992).

Community participation

It has been argued that much of current practice in telehealth “perpetuates a tyranny of one-way communication” in which a basic position or recommendation from an expert group is adopted and disseminated throughout the system (Williams, Ricketts & Thompson, 1995). Again this need not necessarily be so. Information and communication technologies can just as easily be employed to support community participation.

The Tanami Network is a 7-site, satellite-based videoconferencing network established in the early 1990s in Central Australia. This Aboriginal-owned and controlled network is used regularly for family, community and ceremonial contacts. Areas of service delivery include telehealth as well as secondary and adult education, court hearings, and consultation and planning meetings (Toyne & Granites, 1995).

Recent personal experience demonstrating telehealth to Aboriginal communities in far north Queensland (part of the Balkanu Cape York Technology Exposition) confirmed, for me, the value of this technology to these groups. The response of the indigenous health

workers and community members was overwhelmingly positive. This is in stark contrast to the views of some non-indigenous health service providers who consider that telehealth is not an appropriate means of service delivery for Aboriginal and Torres Strait Islanders because they are not technologically sophisticated (Lessing, 1999). In the STARPAHC Project, the local Native American community was involved in the design of the project as well as setting evaluation criteria and benchmarks (Bashshur & Lovett, 1977).

Conclusion

The world at the beginning of the 21st century is very different in many ways from the world at the time of the Alma Ata Declaration 23 years ago. Many of the most dramatic changes have resulted from advances in information technology and communications. Telehealth is just one aspect of this 'communications revolution'. Applied appropriately, i.e. with due attention to equity, prevention, appropriate technology, intersectoral action and community participation, it has great potential to support primary health care and, thus, to contribute to the goal of 'health for all'. What is required now is research demonstrating the clinical, educational and cost-effectiveness of telehealth applications in the primary health care context.

I will leave you with a paraphrase of the words of Dr Gro Harlem Brundtland, Director-General of the WHO, who used the term 'telemedicine' where I would use 'telehealth'. In reaffirming the WHO's commitment to telehealth at an inter-country meeting in Saudi Arabia last year she said "I am a promoter of (telehealth), but even more so a promoter of equitable, quality health services to all people. (Telehealth) is merely a way to achieve that" (Brundtland, 1999).

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Telehealth - engaging the community in its acceptance and delivery

Ms Helen Cooper

Deputy Mayor, Flinders Island Council, Tasmania

I feel somewhat inadequate standing here at a Commonwealth *Health Online* Summit – for my background is not as a health provider, but as an end user of the technology you have devised, refined and delivered to rural and isolated communities such as the one I represent. Nevertheless, any product that requires marketing needs an end user and it is these customers or consumers that I speak on behalf of today. I was going to say that I had been asked to present the ‘grass roots’ perspective of telehealth, but with the current program on the ABC and my background in local Government, the analogy no longer seemed appropriate!

Flinders Island? Where is it? - I hear you ask. And, for those of you who are immediately thinking ‘cheese’, ‘cream’, or maybe ‘beef’ - **WRONG!** That is another island on the other side of Bass Strait. No free advertising in this presentation! When you hear the name **Flinders**, think – 40 degrees south – spectacular natural beauty – over one hundred isolated, pristine beaches. Think of a place that does not know the meaning of the words ‘traffic jams’ or ‘peak hour traffic’ – where hustle and bustle is replaced by a ‘busy-ness’ of one’s own making – and where the quality of life is unparalleled!

Flinders is the largest of the 52 islands of the Furneaux Group which lies off the North East Coast of Tasmania in Bass Strait, some 160 kilometres, as the crow flies, from the nearest city and service centre of Launceston. Approximately 900 people live on Flinders – with another 50 based on Cape Barren Island, the second largest island to the south.

Flinders is fortunate to have a resident District Medical Officer, affectionately known to all as Dr. ‘Bob’, who is on call 24 hours a day, seven days a week. His practice is based at a small, up to date medical centre, named by the State Department of Health, in its infinite wisdom – a Multi Purpose Centre – thus ensuring that almost every visitor has to **ask** where the Medical Centre / Hospital / Community Health Centre is! The M.P.C. has 5 acute beds and 8 nursing home beds. The Site Managers have been enthusiastic supporters and drivers during telehealth’s introduction and acceptance process.

Having a doctor who is a sole practitioner means that all surgical cases are sent off-island, as are all maternity cases. Specialist support is provided by quarterly visits from an orthopaedic surgeon, a gynaecologist, and a dermatologist. Additional specialist services are provided on a demand driven basis. Other allied health services – physiotherapist, dentist, osteopath, social worker and occupational therapist visit on a regular basis. As you can see, the staff at our Multi Purpose Centre works very much as a primary health care team.

The State Air Ambulance Service, a medical retrieval service, based in Launceston, provides the necessary 24-hour support for emergency evacuation. Now, with the introduction of telehealth, immediate connection to the Emergency Unit at the Launceston General Hospital is available – with the camera being operated from that end, allowing the sole practitioner 100% concentration on the job in hand. So you can see that we are a community which is well suited to telehealth and which stands to benefit from what it has to offer.

When we were offered the chance to install telehealth equipment and become part of the initial network linking remote areas of Tasmania, we jumped at it. Thanks to an enthusiastic team, capably and dynamically led by Ros Hill, a **PC based telehealth system** was quickly installed– with the added bonus of a document camera and a diagnostic camera.

Our **challenge** then was how to **introduce the new equipment** to the community – to get them **involved and on-side**.

First we had to address the inevitable, initial scepticism.

- Was the introduction of a telehealth facility an attempt by ‘Government’ to reduce its ever-escalating health service delivery costs?
- Was it planned as an eventual replacement for face to face consultation?
- Would it threaten the provision of a resident GP to the Furneaux Group?
- How would telehealth protect patient confidentiality?
- How would privacy be ensured?
- Would it be affordable?

We made it our **top priority** to reinforce the message that **telehealth is a tool to enhance present service delivery** to its consumers, whilst playing a major role in alleviating the isolation of health professionals based on the Island. We have constantly emphasised telehealth is a **health tool, not** a master. We have demonstrated that telehealth has the ability to reduce the **dislocation to everyday life** for those requiring certain types of specialist consultation – for **pre-admission and post-discharge** for procedures requiring hospitalisation – and **for monitoring and providing support** through clinics and support group linkups. And, of course, it is **wonderful** for family link ups when the patient is hospitalised off island, and for introducing the new family member, born in Launceston, to the brothers and sisters waiting at home! How one measures the **well-being factor** for both **patient and family** in these situations, I’m not sure, only to say that it’s **positive** and heart-warming!

We saw our task as needing to demonstrate its benefits whilst allaying the community’s fears. To this end we planned an Open Day Launch, and invited community groups and individuals to come along and see what telehealth had to offer – but **after** all the necessary Pollies and dignitaries had departed! We engaged their commitment by offering to train representatives from these groups in the use of the equipment. With their

newfound knowledge, over thirty individuals became **positive advocates** for the technology within our small community.

We featured real cases – for the human, feel good touch - and were lucky to have a willing participant and a natural charmer in young Alexander Holloway who is 7. Alex suffers from Von Willebrand's Disorder, with his blood having a deficiency of the clotting factor 8. Alex, accompanied by his mother Karen, is required, on a regular basis, to travel to Hobart, some 400km away by plane and bus for the monitoring and management of his condition. Apart from the cost, this causes obvious disruption to family life, to the other children and to employment of Alex's parents, as well as to Alex's schooling, though, just maybe, young Alex doesn't see it that way!

Also, advantage of the occasion was taken to announce the University of Tasmania's decision to base a Rural Health Teaching Site at Flinders Multi Purpose Centre. This lifted **our** profile, by emphasising that the Teaching Site would be dependent on the ability to utilise the telehealth facility. Having future health professionals receiving part of their training within our community has bolstered confidence in the existing staff and facilities, whilst arousing immediate interest and curiosity in the operation of telehealth. We were fortunate to have Professor Judi Walker, from the University of Tasmania's Department of Rural Health, as the driver of this project.

The Furneaux Group has been extremely fortunate to have Dr. Bob as its Medical Officer for the past 26 years. However, as a community, we realise that the recruitment of a Medical Officer is an issue we will have to deal with 'somewhere along the track'. Having a **well - established and well utilised** telehealth facility as an **integral part** of medical service delivery in the Islands, will be **paramount** in addressing the '**professional isolation**' concerns of any medico we are likely to attract. Already the nursing team at the M.P.C. has found the facility invaluable for the provision of on - going staff training and professional development.

We also demonstrated how other services could be accessed – **Centrelink**, accessing its officers for information and assistance, **Justice Department** - for the taking of pleas and other procedures where physical presence in court is not required - and for JP training, **Education** – by showing parent/ teacher/ pupil link ups with island students at secondary colleges on mainland Tasmania. **The Volunteer Ambulance Unit** on the island showed the benefits of being able to access their peak body for professional support and for training sessions, a feature that is constantly being utilised. The advantages of the **diagnostic camera** for wound management purposes, were demonstrated, with a patient, who had recently undergone hip replacement surgery, linking to the orthopaedic surgeon in Burnie, for a post operative check. **Wound management** is an area that has already shown great benefit and potential. To reflect this **broad**er range of uses, we named our facility **TELEACCESS**. We see it as **our access** to **off island** services. We took the view that **anything that reduces the stress and trauma** caused by **isolation** and **dislocation**, **increases community well being**, and so, is basically a health issue.

Our day was a **resounding success** – from young Alex showing his new tooth to ‘Sister Sue’ at the Royal Hobart Hospital’s Paediatric Oncology Clinic– to the Flinders Island parents showing the family dog’s puppies to their daughter at boarding school in Launceston. Not only was the weather kind – so was the technology – with a score of link-ups seamlessly presented and achieved by a dedicated team at each end! As a result, the grapevine flourished, with dozens of **positive** stories– and those of you who know small communities, will appreciate what a **powerful tool** that is to have on-side!

There is no doubt telehealth is a fantastic tool – the potential of which is possibly only limited by our imaginations. Already the staff at the M.P.C. has expanded its use to set up a regular telehealth **Diabetes Clinic**, accessing the Launceston General Hospital, to cater for the **higher than average** number of clients with this condition on the Island. We furthered this type of use to assist clients with **renal** conditions as well, and have begun a **dermatology clinic** for assessment and management in between specialist visits.

Palliative care is another field that is now utilising the facility and obviously this has great benefits for patients, their support group of family and friends, as well as the medical staff caring for them. The integration of **pre-admission** and **post-discharge procedures** from the Launceston General has seen an **improved** and **more cohesive transition** for both the patient and the medical staff on Flinders.

The introduction of regular visits by a Social Worker has opened another avenue of benefits to be pursued and refined. With ongoing reinforcement of the **privacy and confidentiality** aspects of telehealth within the community, there is potential for counselling and link ups for support groups in the field of **drug and alcohol dependency, sexual assault and mental health services**.

With the necessity for expectant mothers to go to Launceston for delivery, the facility is proving valuable for both **pre and post-natal monitoring** and **support**. Soon we will be able to provide link up for ultrasound reviews, using guided sonography, which will be particularly beneficial in this area, and, of course, applicable in many others, but which currently necessitate travel off island.

We are excited at the proposed expansion of telehealth within our island community, with sites soon to be installed on two smaller islands in the group, Cape Barren and Clarke Islands, thus improving access and service delivery for their predominantly Aboriginal communities.

However, I can see a couple of small clouds ahead on telehealth’s sunny horizon. – or perhaps I should call them small challenges for us to address and tackle.

Firstly, in any service delivery the bottom line is the \$ - and for the service to be maximised this cost factor has to be addressed. **Affordable** and **reliable** telecommunications are **vital if rural and remote consumers are readily to accept and utilise telehealth**. Being without ‘phone, fax or connection for 4 ½ days of the working week, as I was only last week, or rarely being able to send an e-mail after 7pm, does little

to persuade isolated health consumers that services, delivered via telehealth will be **reliable**, and **be there**, when required. There is a need to provide **equitable** access to those who need it most – those who already have the **barrier** of **distance** and **isolation**. These people feel that the burden of **additional cost** to access the services that their urban counterparts regard as **basic** is neither **equitable nor just**. So our goal is to have local call rates for our ISDN line – and we aim to make it a reality!

This mention of **equitable and affordable access** brings forth another issue. For people in rural and remote areas to achieve this, access must be **expanded** to allow a **wider range of specialists** to provide remote client consultations. How valuable it would be, **if reimbursement through Medicare** could **also** be **expanded**, for specialists who are willing to use telehealth for non face to face consultation with remote health consumers! If an item for such consultations were to be included in the **Medical Benefit Schedule**, providing incentive of payment, access to a wider range of affordable specialist care would be possible, for the rural and remote consumer, ensuring quality of access and promoting earlier interventions.

Secondly I feel there is a need to **listen** to the communities and individuals that are the **end users** of telehealth. It is most important to maintain customer focus – and, to some degree, be customer driven. It's all too easy to get bound up with the **delivery of 'you beaut' technology** without consideration of the ultimate user or consumer, and so, in the process, embark on the dangerous path of deciding **what's good for people**.

From my experience in Local Government, this approach is flawed and will undermine the long-term sustainability of any project, and even doom it to failure. **Nothing condemns** a project more than **telling** customers that what's being delivered is what they need – particularly when **they** have to **pay** for it!

In Local Government, a Council that **consults** and **listens to its community** is **responsive** to its needs – and a **responsive Council** generates **community well being** and **survives!** I'm sure the same basic principle applies to telehealth.

It is important for Project Drivers to **listen** to consumers – their needs, their concerns, their ideas – [you never know – they might have some good ones!] and to work **with** them – engaging their support and harnessing their energy and enthusiasm.

So I see **meaningful consumer input**, into **all levels** of the planning and delivery of Telehealth, as **essential**, from the **top national perspective -down** to the local level. Input from those who **depend** on telehealth as a tool for the delivery of their health services in rural and isolated areas. Customers may not always be right, but we must let them think they are! – by valuing their input and so addressing their needs. Only then will we ensure **maximum acceptance** and **maximum utilisation** of the services that can be provided.

We, in the **Furneaux Group**, are delighted to be part of the development of **telehealth**, a network that is about **people and services**. **Telehealth Tasmania** is focused on the

provision of **equitable access** and **appropriate service delivery** to **remote health consumers**, whilst giving **professional support** to the health care workers practising in these areas.

Our community has become a **strong advocate** for telehealth because its members were **intentionally involved** from its **inception**, creating **awareness of its potential** and **building 'ownership'**. This has been **reinforced** by the **positive experiences and results** that telehealth has delivered. We look forward to the ongoing development and enhancement of this **terrific, exciting tool - TELEHEALTH !**

Telehealth

Ms Maxine Drake

WA Health Consumers' Council

Abstract

The provision of health care through interactive electronic media is currently occurring, in varying degrees, throughout Australia. The absence of national standards and a code of ethics to guide this activity is a serious concern for consumers.

Standards guiding the development of telehealth need to recognise two particular domains. The first is the decision-making process within which a decision is made to place telehealth facilities in particular regions. The cost of installation and upkeep need to be considered in relation to the recruitment of health professionals in these areas. Consultation with communities in advance of establishing telehealth is critical to acceptance of the technology. Consumers in rural areas are faced with long waits to see visiting specialists, or significant expense if they take themselves to metropolitan centres. Telehealth offers an alternative model for service provision but does not come without the political taint of the 'people versus machines' debate.

The second telehealth domain that should not proceed without an ethical practice framework is that of clinical consultations via telehealth technology. Consumers are the subjects of experimentation at present in a manner that may be considered to be ethically unsound. The quality of communication in clinical consultations is the pre-eminent consumer concern within conventional health care environments. We need to ensure that the seductiveness and novelty of the technology does not cloud our capacity to be critical of what it can deliver in terms of quality care.

INFORMATION FOR DECISION SUPPORT – ENHANCING DECISION SUPPORT

Enhancing decision support

*Dr George Cerchez, NHIMAC Representative and
Australian Divisions of General Practice and GPCG Representative, Tasmania*

As a general practitioner who has been fortunate enough to step outside the cloistered medical environment, into the world of information technologists, computer programmers, merchant bankers, and the business world generally, I continue to be confronted with the uniqueness of my profession in relation to making decisions. I have observed that it is extremely unusual in any of these other professions, and industries to be faced with so many time critical decisions which potentially could have such major implications on people's lives. As a general practitioner, one is faced with up to 30 or 40 such decisions per day; each of which will affect someone's life. Even not making a decision has its consequences – there often is a time for intervention, which can be critical.

To add to the difficulty, like 20,000 of my colleges around the country, many of these decisions are made in isolation from patient information. One of the most frequent and yet critical times that this occurs is at patient discharge from an institution of high cost, high dependency and intervention that we call our public hospitals. Patients are sent back into the community with no information and a 5-day supply of medication such as anticoagulants, after having had major events such as strokes or infarcts, with an expectation of their primary care physician for informed ongoing care.

Geraldine Doogue told us earlier today, “to declare your self interest,” so I will declare mine. What started my personal journey down the long and tortuous road of information management some 8 to 10 years ago was the quest for patient information to support and enhance my decisions. The first and most critical component of any decision is the assimilation of information. A decision is only as good as the information on which it has been based. This critical concept should not be overlooked in the technological world of decision support.

Decision support can be classified as passive or interactive.

Passive decision support is currently in common use and includes electronic books which provide ready access to data such as product information and guidelines. Access to such data sources can now be obtained over the Internet.

Interactive decision support – at the lowest level this consists of simple rule based systems such as dose calculators, and drug interaction alerts.

More complex interactive systems draw on information from the patient record and knowledge bases such as integration of a cardiac risk assessment system with clinical data from the patient record to provide advice to doctors on whether to initiate risk factor management programs.

The ideal decision support system would be one where a key word entry such as a diagnosis within the existing practice management system, and relevant databases should interact with relevant patient management guidelines to provide the doctor with the opportunity to access advice to inform their decision at the point of care.

Decision support tools are finding their place in four key areas of health delivery in general practice today:

- prevention
- chronic disease management
- prescribing
- diagnosis

Prevention

The most basic system in use in general practice is the patient recall or reminders system. In this situation, patients are tagged to prompt the user to perform some preventative activity like an immunisation, blood pressure check, diabetes screen, or diabetes prevention protocol. This has been well adapted into most general practitioner software but is used to a variable degree by the nation's general practitioners. Accreditation of general practices is encouraging its use and computers assist in this process.

Tools built into software programs such as cardiovascular risk calculators, diabetes modules and patient education material are also reasonably common.

Chronic disease management

There are a number of exciting electronic initiatives occurring in this area, but what is required is a systematic coordination and identification of these advances. The validity of the guidelines or protocols is often unproven with evaluation of the impact and outcomes generated by such electronic decision support also poorly lacking.

Another problem is that general practitioners often suffer 'guideline overload' in the paper-based world. These multiple guidelines often line the shelves in the surgery and home and are seldom accessed due to time constraints. In the ideal world, the electronic presentation of a guideline in an updated format at the point of care should affect and prompt a clinical decision and ultimately provide an improved health outcome. Progress is being made but there is still a long way to go before a workable system is achieved.

Prescribing

In general practice systems, this represents the most widely used and mature of decision support processes. It also clearly presents an example of what the combination of incentives through the Practice Incentive Program, software developers, and the development and application of clear guidelines, can achieve. Improved application of the Quality Use of Medicines principles should occur – this topic will be more fully explored by Ken Harvey later in this session.

Diagnosis

This obviously is the most complex of decision support systems and will provide the clinician with the most benefit if perfected. We are a long way off the Utopian system where a patient is plugged into a computer to provide a diagnosis of the problem. There are, however, a number of programs which will formulate a differential diagnosis as well as rule in or out a diagnosis. This occurs through a process of review of history, signs and symptoms, laboratory results providing a review of disease profiles, complications and associated disorders. There are several other variants available through international companies, but their use in Australia is extremely limited.

The acceptance of e-health on a large scale by clinicians will depend very much on the ability of the new technology to not only improve clinical outcomes, but to do so in a way that is sensitive to the time critical requirements of the patient consultation. The potential benefits are considerable, as the increasing complexity of the medical and medico-legal environment will give rise to opportunities to remind, reinforce and support the decision process for the clinician. While it is unlikely, and undesirable that decision support tools will replace the 'art' in medicine, the computer excels in pattern recognition and reminder functions which are a key feature of the multiple transaction processing which is undertaken by clinicians during consultations. Value will be delivered to all stakeholders – the consumer, the health professional, governments, service providers and funders – by the application of principles that are strongly evidence based.

The aim ultimately is to get the electrons to do the hard work!

Enhancing decision support

Mr Craig Patterson

Director, Health Policy Unit, Royal Australasian College of Physicians, NSW

Abstract

The Clinical Support Systems Project (CSSP) integrates the methodologies of clinical practice improvement (CPI) and evidence-based medicine (EBM) and is investigating how to embed best practice routinely in clinical care, utilising improved clinical support systems including information systems.

Enhancing decision support

Dr Chris Baggoley

Chair, Committee of Presidents of Medical Colleges, Victoria

Thank you for the invitation to talk on the subject of enhancing decision support in the context of this *Health Online* Summit, particularly with reference to emergency medicine. Support, for clinical decision-making, can occur in two broad areas. Information systems can assist in better understanding the patient and they can assist in understanding and managing the disease process. I will concentrate on the former, as it is the area of greater need. I would acknowledge that the increasing utility and availability of poisons information systems have been particularly helpful in emergency department management of overdose and poisoned patients.

The journal *Healthcare Executive*, just published, has a focus this edition on information technology matters, including a substantial chapter on enhancing medical records. This chapter included a section on physician participation. It noted:

“One of the most important factors when implementing major change in a healthcare organisations is gaining physician buy-in. Because transitioning to electronic medical records will dramatically affect physicians day-to-day activities, it is all the more important that they be involved in the planning process and educated on the benefits that such a system will provide.”

“To make these systems work well and be a positive enhancement, you must do everything possible to add value for the physician and their patients. If you can show them that the system will facilitate care, provide more data, and save them time, they will be more accepting of it.”

The article provided as a Case Study, the Queens Medical Centre, Honolulu, the largest private hospital in Hawaii, with 530 acute care beds and 1000 doctors on staff. To ensure the system would be useful for doctors and to help gain their buy-in, the organisation employed six of their doctors on a part time basis to work on the planning and implementation. These doctors were recognised as leaders among the medical staff. They were not ‘computer jocks’. As their medical director for information explained, you don’t need technical experience from the doctors – others can provide this – what you need from them are good clinical reputations and the people skills that will help bring on board other doctors who would otherwise be resistant.

As I have indicated, I have been asked to speak from the perspective of emergency medicine. When I told my fellow Australian College of Emergency Medicine Councillors last week that I had been invited to speak at the *Health Online* Summit this week there was stunned incredulity. As one, they said – ‘but you don’t know anything about *Health Online*’. I did point out that ignorance on a topic had never prevented my

speaking previously and that my definite status as not being a computer jock would, according to the literature, afford me considerable status.

Besides, I had supervised the Committee of Presidents of Medical Colleges' submission to the inquiry set up by the National Electronic Health Records Taskforce and I had a copy of their subsequent report.

The fact is, even the most computer illiterate emergency physician is exposed to, and utilises computers in their everyday clinical work, and they are also systems people. They understand that their clinical input has to be seen in a systems context. To be successful, they must relate well, not only with a patient they may meet only once, but they must also rapidly gain as much information as they possibly can from their patient, the family, the ambulance service, their general practitioner and other community organisations involved in their care so that they can put this acute episode in an appropriate context.

They must undertake the appropriate clinical work then place their patient safely in the right system – be it hospital, home, other facility, hospital at home, other family care. They need as much information as is available, as quickly as possible, in as organised a manner as possible, to be effective.

Current computer systems available to emergency physicians by and large assist in the delivery of information stored in the hospital system. As Dr Mowat pointed out in his opening address yesterday, most information held is about hospital care, yet there is a massive swing away from in-patient care. Little by little, and in an uncoordinated fashion, other linkages are being forged. While faxes from general practitioners about their patients are commonplace in some areas, I am told, e-mail notification is emerging. Medic-Alert bracelets are being computerised so that, with the right reading system, a wealth of clinical material carried on a patient's wrist can be obtained.

At Flinders Medical Centre, just 10 kilometres down the South Road here in Adelaide, where over 50,000 patients per year are cared for in the Emergency Department, computers have been used to assist patient flow and clinical management, for well over a decade. It is the integration with the hospital's pathology laboratories, medical imaging department and medical records departments that provide excellent clinical support in emergency situations. It is the patient's hospital identification number that, when entered into the triage computer, immediately enables patient alerts and special treatment programs to be flagged. It immediately provides access to the list of previous attendances, to laboratory and radiology results stretching back several years and to discharge summaries written over that period.

The discharge summary provides relevant medical history, drug schedule and allergies and advice as to the treating specialist and the patient's general practitioners. That information on treating doctors is available elsewhere as well - all available as the patient is being placed into a treatment cubicle, so that the treating staff can hone in on those events that lead to this presentation, armed with the knowledge and context of prior

events. If blood tests are taken, a marker appears by the patient's name on the computer screen when results are available, brought onto screen by the push of one button.

When the patient's treatment in the emergency department is finished, staff enter international classification of disease codes from diagnoses made, using a simple, logically devised key word system. With patient's consent, relevant material from the emergency department attendance is faxed to their general practitioner on a daily basis.

Not all computer systems in our hospital Emergency Departments are so useful. Some serve merely to ensure that patient tracking and data collection functions are satisfied and lack the integration with hospital pathology, radiology and medical records systems to provide real clinical benefit. Integration is the key. Integration with information stored in the community is not available.

Health Online is the logical next step – not a huge one in functionality for some of us, much greater for others. Over 4¹/₂ million patients attend emergency departments in Australia each year. More than two thirds of these attendances occur outside regular office hours of patients' general practitioners and specialists. While I have portrayed the excellence of an integrated system for patients well known to one hospital, this system confers much less benefit for a new patient or for the patient whose contact with the hospital is not recent.

The Taskforce provided several scenarios portraying the benefits of a health information network in an emergency department situation. One in a trauma situation, one demonstrating the potential for adverse events when information is hard to come by – that is, in those out-of-hours situations – and the third, the value of such a network when a patient cannot communicate. They used the situation of a patient in a coma, but the mind altering effects of drugs, the effect of stroke, the effect of severe toxicity or pain even, or something as simple as a language barrier all can profoundly impair effective communication, so helpful in emergency situations.

Now the scenarios look like a journalist, trained at the Hans Christian Anderson School of Journalism, writes them but they have a touch of realism to them.

I attended an elderly lady at 3 o'clock this morning. She was feeling very unwell, was short of breath and had a rapid pulse. She had multiple medical problems, which included coronary artery disease, diabetes, asthma, hypothyroidism and was on 19 different medications.

She felt much better after vomiting a litre of fluid and wanted to go home. Unfortunately her blood showed a very significant deterioration in renal function since she had been last seen in the hospital a year earlier. Access to a health summary from her general practitioner or to laboratory tests taken at a different provider could have saved her four hours of emergency department observation before her general practitioner could be contacted. An acute deterioration would have different management implications than a

chronic deterioration. No harm was done from the wait, but it was an inefficient use of her time and of the emergency department staff function.

A system which enables concise, correct health summaries to be transmitted to a hospital emergency department, which overcomes communication barriers, which reveals potentially life threatening underlying illnesses, allergies or medication combinations will assist in the saving of lives and will reduce the incidences of adverse events. A system that enables results of tests, images of x-rays or electrocardiograms to be transmitted from external agencies to a hospital emergency department will save patient discomfort, investigative time and the expense of duplication of tests. It, too, will reduce adverse events and will improve Emergency Department efficiency.

The same benefits will apply in reverse. The Emergency Department attendance will result in new tests, new diagnoses, new therapies and often, new tasks for the patient's general practitioner and community support worker. If the outcomes can be returned just as quickly to these agencies, then the continuum of patient care can continue with lesser risk to the patients. Not only are patients discharged home sicker from hospital wards these days, the same applies to discharges from Emergency Departments, where for each patient attendance a computerised summary is already being generated.

I cannot conceive a down side of a well functioning health information network for those 4½ million patients who attend our emergency departments each year and I believe the best examples of the functionality of such a network are found in emergency situations. For the Emergency Department personnel the technology is becoming commonplace. Even a non-computer jock like me can function well in such a system and become an advocate for change in this direction.

Before I finish, I might make a few observations on broader College views. It has been pointed out that, in contrast to emergency physicians, for an electronic health record to become a reality will require large changes in practice for many providers. Sceptics do query the assumption that electronic health records will improve the efficiency, safety and quality of care compared with paper based records, asking for the evidence of such an assumption. In addition, to quote one College, 'information system projects all around the globe have a high failure rate'. Dr Mowat put the figure at a 60-70% failure rate yesterday so these sceptics are in good company.

For Colleges, matters of privacy, ownership of records, development of health summaries and obtaining consent of consumers for transfer of aspects of their health record are all complex issues which will continue to warrant serious and lengthy analysis.

Thank you for your attention to an audiovisual aid free presentation.

Information for decision support: therapeutics

Dr Ken Harvey

School of Public Health, La Trobe University

Australia is currently highly regarded internationally for its medicinal drug policy, especially the quality use of medicines (QUM) pillar developed by the PHARM Committee, now assisted by the National Prescribing Service. PHARM developed a number of strategies to assist QUM. These included developing partnerships and supporting the development of independent therapeutic guidelines and drug information, ethical promotion, medication review, capacity building and education. The main mechanism for implementation was a competitive grant and scholarship program. The strategy has been remarkably successful, for example, antibiotic use in Australia is now declining, as has the use of non-steroidal anti-inflammatory drugs (NSAIDs), and medication in aged care facilities is much improved. A number of studies show that direct dollar savings are at least 10-20 times the amount invested.

Ironically, E-medication services have so-far developed in isolation from the above. PHARM clearly defined a basic set of information resources required by the competent prescriber (and consumer). However, there is currently no master plan to convert these into common electronic formats and ensure they are incorporated into prescribing software, let alone define the research needed to achieve computerised decision support by the interaction of these resources with the emerging electronic medical record. In addition, neither State Call Centres nor the Commonwealth's Consumer Web portal, *HealthInsite* use these information resources. PHARM clearly identified ethical promotion as a key plank of QUM. However, the pharmaceutical industry has been allowed to substantially infiltrate prescribing software with advertisements for the latest and most expensive drugs. Finally, although PHARM worked hard at achieving partnership, recent initiatives such as the \$133 million dollar Better Medication Management System (to link consumer medication records between physicians and pharmacists) appear to have developed largely in isolation, not in partnership with what has gone before.

I see two scenarios ahead. In the first, Australia will lead the world using information technology to further enhance quality use of medicines (QUM^{IT}). This will generate considerable export earnings through licensing our innovation in knowledge distillation, database generation and decision support software. In the second, if we continue as we are, it will be Malaysia (or China) that will reap the regional E-medication harvest, not Australia.

BUILDING A BETTER EVIDENCE BASE FOR HEALTH CARE DELIVERY

Building a better evidence base for health care and delivery - a consumers' perspective

Fiona Tito

Director, Enduring Solutions

'Consumer participation', 'care partnerships', 'joint decision-making' - all the rhetoric is going in the right direction! But for many consumers, that's as far as it goes (if it gets that far!) All of these things require access to good quality information at the right time and in an understandable manner - and often none of these prerequisites are met for many consumers of health services.

As an example, I have often heard clinicians say that they tell patients information and the patients don't listen or forget it as soon as they walk out the door, so why bother? I point out to them that this really indicates a failure in their communication approach rather than anything about a consumer's desire to know. All the research and anecdotal information indicate that doctors generally underestimate how much consumers want to know. What happens is a failure of communication because the person with the information (usually the doctor) is not sensitive to what they are saying and when. The scenario from a consumer perspective may often be that they are sitting (sometimes incompletely dressed) with a high degree of apprehension and the doctor tells them his or her suspicions/conclusions, which may be quite devastating. A consumer will often then go into automode - hearing nothing after the diagnosis word is said, particularly if it something like 'cancer'. To help clinicians understand what it feels like, I talk about when they get a phone call from where someone is accusing them of medical negligence. Often once the word 'sue' is heard, they have the same response.

Then, there is also the language chosen - the doctor may use medical terms with little explanation and often be unaware that the consumer is only vaguely aware of what bit the doctor is talking about. I am a highly educated consumer, but I really am not sure where all the glands and organs in my body are (or how big or small they may be!) I still refer to everything below my waist as my tummy or my stomach, though I know that the specific organ lies elsewhere. Using the litigation analogy again, if the person who rings the doctor is a lawyer, often the words used are foreign or have a different non-legal meaning so the doctor really doesn't know what is going on and is very anxious. In both cases, there needs to be better ways of communicating rather than the information-giver assuming that the information-receiver is not interested or too stupid to understand. People need time to think about information of that kind, to read or talk about it and then ask questions - it takes time for it to 'sink in'.

The rhetoric also says that good quality information must be evidence based. For those of us who have looked at health care searching for the 'evidence', we are aware of just how much of health care has not got such a base, or at least not at the so-called 'gold standard' Randomised Controlled Trial level. In addition what is evidence-based from a consumer's perspective may include different things than are discussed by clinicians - the old 'the operation was a success, but the patient died' quandary! In a very recent letter to the British Medical Journal (BMJ), the United Kingdom Centre for Health Information Quality gave three dimensions to what is considered evidence-based information from a consumer perspective. The three dimensions suggested were:

- rigour;
- relevance; and
- completeness.

Rigour is the traditional concern of organisations like the Cochrane Collaboration and the creators of guidelines. While it is fundamental to good information, it is not sufficient. The BMJ letter went on to say:

“The content of what is found is important: its relevance to patient's concerns and its completeness.

If information is irrelevant it tells you something you didn't want to know - for example, about treatments unavailable locally or not reimbursed by your health system. If information is incomplete it doesn't tell you what you want to know. If information is incomplete it doesn't tell you all you wanted to know. For instance, women often don't take iron pills in pregnancy because they get constipated and assume that this is the effect of the iron. At present the Cochrane Review of iron supplementation doesn't mention constipation, and the review of methods to prevent constipation doesn't mention iron; women's concerns may be addressed by a review currently under way.”⁵

I found the same thing when helping my father when he was being treated for cancer. In Dad's case, the pamphlets he was given, when he was told that he would be best served by chemotherapy for his inoperable stomach cancer, gave him the risks and side-effects as required by the law, but almost nothing else of use. It didn't talk about the effectiveness in treating the particular cancer (or even suggest that this was a pertinent discussion point with his clinician). It didn't tell you how the stuff got into you, or give you choices about that. Dad was advised to have a port-a-cath to administer the chemotherapy, but how that worked and what the bits were that were inserted remained to a large extent a mystery. I was disconcerted one day at arriving at the hospital to see three old men sitting on one of the beds trying to work out what the 'machinery' was that

⁵ Milne R, Booth-Clibborn N, Oliver S. Consumer health information needs to be rigorous, complete and relevant. Letters in *BMJ* 2000; vol 321: page 240

had been put in their bodies. They were all tradesmen and engineers, but they still were trying to work it out without any help from clinical staff.

And once you look at what 'counts' as evidence, from a consumer's perspective, in many cases, there are real issues about how relevant the 'Gold Standard Evidence' is to your particular clinical situation. For example, the groups used in randomised control trials may bear little resemblance to you (with all those inconvenient 'other' things you have 'wrong with you', or your other needs as a working person or carer or whatever). Equally, the doctor you have access to is more than likely not one of the highly trained experts who got excellent results in the randomised control trial, but someone who is more 'average' in their skills and experience. What relevance then is the information from the randomised control trial or series of randomised control trials to you right now at your decision-point? What does it REALLY tell you? And what of all the alternatives which it may not have looked at?

There is also a range of limitations on the use of randomised control trials for certain procedures.⁶ Often there are significant ethical issues - the randomised control trial carried out without consent on women with positive pap smears at the National Women's Hospital in Auckland between 1966 and the 1980s is an example. The Committee of Enquiry set up to investigate the 'trial' found that the women did not know they were on a trial, were not informed that their treatment was not conventional and were given few details about their condition. It seems unlikely that many would have consented or that the trial would ever have got approval today.⁷

To give a less obviously tainted example - what about trialing whether pre-operative assessments are good practice in anaesthetics? Is it really worth the time and money in terms of patient outcomes? I think it would be extremely difficult to get ethics committee approval for such a study. So how do we make judgements in these areas? What is our evidence and how do we 'know'? I am not meaning to downgrade the importance of randomised control trial evidence - more to suggest that they are not the sole evidence base upon which health care and health care consumers can depend. They are like the Rolls Royce in certain areas, but like Rolls Royces they perhaps are not suitable for all purposes - nor could we afford them to be the only option! Sometimes we need our

⁶ A summary of some of these criticisms can be found in the Review of Professional Indemnity Arrangements for Health Care Professionals' *Compensation and Professional Indemnity in Health Care - A Final Report*, Commonwealth Department of Human Services and Health November 1995 Canberra (PIR Final Report), paras 3.31-3.43, pages 42-45. A copy of the PIR's Final Report can be found on <http://www.health.gov.au/pubs/hrom/theainsu2.htm>.

⁷ For full details of this matter, see Committee of Enquiry into Allegations Concerning Treatment of Cervical Cancer at the National Women's Hospital and Other Related Matters, *The Report of the Committee of Enquiry into Allegations Concerning Treatment of Cervical Cancer at the National Women's Hospital and Other Related Matters*, NZ Government Printing Office, July 1988 Auckland.

relatively cheap but reliable Toyota or even a bike or bus to get around - but any vehicle we use or rely upon needs to be road worthy. So it is with all forms of clinical evidence.

An example of this quandary for a consumer is evidence based upon large scale outcomes 'trials' such as the Medical Treatment Effectiveness Program Patient Outcome Research Teams (MEDTEP PORT) trials in the US⁸. These were originally funded by the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality). The first round of research were not randomised controls and thus are likely to be criticised by the evidence aficionados as 'second rate'. Yet they may be the only way outcomes can be checked across a population and a range of therapies. The low back pain PORT trial is a good example⁹.

Equally where does the randomised control trial evidence come from? How can a consumer tell if the trial which supports the conclusion was done appropriately? How can they tell if the results are significant? Given the poor quality longer-term follow-up after treatment, how do consumers have confidence that the procedure or drug delivers its benefits without long-term health care disadvantage? Given the cost of running multi-centre, or even single centre randomised control trials and the push to industry funding, how do we know the research is actually independent: while these are some of the matters which the Cochrane Collaboration looks at in deciding how good the evidence is, there are many health issues which have not been assessed in this rigorous manner.

There are many examples in another area that I have been investigating (the long-term success of weight management strategies) that industry-funded research results in industry-supportive conclusions¹⁰ - but how do I, as a consumer, make judgements about those sort of things? It is difficult enough as a health professional to look at such research and critically analyse its validity. Often what is NOT said is as important as what is, and yet knowing where a question has not been asked that should have is a much more difficult thing to work out and often implies either a greater understanding, doggedness and time/resource commitment than consumers can possibly be expected to put to the search for quality information.

As we move more and more away from Government to industry funding of research, the issue of the 'independence' of the research becomes more critical. There are many

⁸ For more background on the program see the PIR Final Report - paragraphs 3.44-3.48, pages 45-46.

See also the Program web-page : <http://www.ahcpr.gov/clinic/medteprp>.

⁹ The findings of that research have been formed into a Clinical Practice Guideline - see : <http://text.nlm.nih.gov/ftts/tocview>.

¹⁰ For general discussion of funding of obesity research by the weight loss and diet industries, see Fraser, L : *Losing it : America's obsession with weight and the industry that feeds on it*. 1994 Penguin/Dutton New York. See also Berg F. *Women Afraid to Eat - Breaking Free in Today's Weight-obsessed World*. 2000 Healthy Weight Network US, see esp Chapter 10: How the diet industry exerts control.

examples in the US of the funding of key academic positions and research studies by pharmaceutical and other ‘treatment’ industries. It is difficult as a consumer to determine whether or not the research conducted under these conditions, by health professionals whose livelihoods can depend upon the industry funding, is really ‘evidence-based’. When public health policy is based upon such research, which may have shaky evidential foundations, then consumers are often left wondering how they can actually decide what information is trustworthy.¹¹

And often options which don’t involve drug therapy, surgical intervention or health care service provision are completely ignored in the research agenda. They are just not researched at all. For example, the long-term success rate of almost all traditional weight loss approaches is appalling, and the evidence of risks and adverse consequences from these traditional approaches are significant. There many people in our society whose way of relating to food and their own bodies are distorted by health and beauty messages about weight, even if they do not suffer from clinical eating disorders. And yet the solutions being offered and the research being done more often focus on drugs to ‘fix’ the person. The traditional public health and health research messages send women and some men into treatments which are big money but have little long term benefit. It is even arguable that promotion of weight loss without proper disclosure of the risks and lack of long term success is unethical.¹²

When people don’t lose weight, they believe they have been a failure and clinicians¹³ and the diet industry reinforce that view. It is much better that it is the consumer’s fault than to admit that the strategy doesn’t work! Fat people become self-hating and believe (despite all evidence to the contrary) that the secret is simply to try harder next time. While there is certainly some evidence about the health risks of being fat, once you are fat, the evidence supporting weight reduction diets as a successful of losing weight long term is extremely scant. Where is the research investigating whether fat people can live healthier, productive lives without going this route? Where is the research into safe ways of exercising when you are large, and looking at the benefits of living actively whatever

¹¹ The US federally funded National Taskforce on the Prevention and Treatment of Obesity was required to disclose its financial affiliations when it wished to publish an article in the Journal of the American Medical Association. Eight of the nine members had positions as chair with significant financial ties with commercial weight loss firms, and significant grants or honorariums from weight loss companies or manufacturers of diet pills. See Berg F. *Women Afraid to Eat - Breaking Free in Today’s Weight-obsessed World*. 2000 Healthy Weight Network US, pages 195-197.

¹² Hawks S. Gast J. “The Ethics of promoting weight loss” *Healthy Weight Journal* 2000 March/April, vol 14 ; available on the Internet at <http://www.healthyweight.net/ethics.htm>.

¹³ See eg Bruere T, O’Connor T. “Attitudes of Health Professionals to Overweight and Obese People” Body Image and Health Inc (Victoria) 1999 Research Summaries, which summarised a range of research looking at these issues.

your size?¹⁴ Where is the research looking at the impact of working on the issue of self-esteem rather than ‘the weight problem’? There is some material available, but you need to really go searching and be deeply committed to asking different questions.

One of my strategies for addressing this issue and working towards a healthier self-esteem has been to stop reading women’s magazines, to stop watching TV and to throw out my bathroom scales. These strategies have worked for me when many others haven’t, and yet I can’t imagine ever getting funding to research such low tech, non-medical ‘self-help’ approaches. As a general thing, Government bodies are reluctant to use consumer-generated data as evidence - for example, there is no consumer reporting of adverse drug events¹⁵. There are few mechanisms yet for consumers to report adverse events, except as a formal complaint.

So where does this leave us in our search for building a better evidence base for health care and delivery? Are we back to a different place with the same paradigm of “Trust me, I’m a doctor”? While I’m sure it’s still better than “Trust me, I’m from the Government” or “Trust me, I’m a consultant”, I think it is fair to say that consumers want to be more sure of the evidence upon which they make choices (and its limitations) rather than treating it as yet another act of faith. There are many examples before us every day that, systemically, health care has not been worthy of the trust once automatically accorded in it. So are we left without hope and imprisoned in ignorance? Fortunately, I think this is not the case, but we are at a gateway where new routes must be taken.

Consumers want more information and the skills to critically judge the usefulness of that information. Consumers want to be involved in determining the usefulness of that information or have other consumers involved so that someone is asking THEIR questions. Consumers want to see information presented to them in ways which they don’t have to have a PhD in the topic to be able to use it. The Internet has all sorts of promise and pitfalls for this. It gives us access to vast amounts of information and the capacity to relatively easily contact other consumers and to share our own experiences. But it can drown us.

There are databases such as the Healthwise Knowledgeable¹⁶ which we have been looking at in the ACT, which attempt to provide distilled, decision-focussed, evidence-

¹⁴ We are currently developing a program in the ACT which looks at this issue and seeks to encourage safe, pleasurable physical activity for large women, through the ACT Women’s Centre for Health Matters. See also Miller W. “Promises we can and can’t make” editorial *Healthy Weight Journal* vol 13(4) - July/August 1999 on the web at <http://www.healthyweight.org/editor.htm#00-1>

¹⁵ A consumer-based program is being established by the Consumer Institute for Medicines and Health - KILEN in Sweden, with the first international conference on Consumer Reports on medicines being held in Sigtuna, Sweden 29 September - 1 October 2000. For information about its work see its website : www.kilen.org. The English version of the Swedish site was under construction at 9 September 2000.

¹⁶ For information and samples of the Knowledgebase, see: www.healthwise.org.

based consumer health information, but the bulk of the information on this site is not 'public domain', except in communities who have decided to purchase access. There are also tools for developing and assessing health information on the web, but again, finding it can be a challenge.

And then there are the many people in our community that are not 'on-line' and who are precluded from access due to poverty or disability. There are also those who have computers, but due to poor infrastructure or technology, have limited access. Just try and use some of the new websites from a computer which is a few years old - or through a rural phone service! The barriers are legion. Equally, where providers of information assume web-access in designing their information dissemination strategies, they unconsciously disenfranchise the majority of the population who might need access to the information.

There is also a need to facilitate the collection and use of different types of evidence. I was thinking myself of the issue of migraine headaches. I had suffered from migraines for many years. One day, I was reading an Aid Worker's health care handbook called *Where there is no doctor*, and it suggested that when the spots started to appear before my eyes, I should take two aspirin, a strong caffeine drink and sit quietly, possibly out of the light. I lived a long way from the city at that time and I couldn't drive because of the spots, so I tried it. I have used it many times since and it works to stop the migraine developing, so long as I do it as soon as the symptoms start. Now I have a rough understanding of the physiology, but I don't know if it would work for others. I know it works for me and it's cheap and convenient and has almost no side-effects. But how would I go about seeing if it helped others? How would you get the evidence to have it accepted as an appropriate first-line treatment in places other than the Third World (where it was the recommended treatment)? In whose interest would it be to set up and fund such a trial?

There are many examples of this kind of thing where health problems may be addressed by non-chemical, non-surgical and even non-health care interventions. And just as there are snake oil salespeople in the pharmaceutical area, so too are there snake oil salespeople in the broader therapeutic or claimed therapeutic community. How can consumers know? How can consumers' experiences be used systematically to build up the knowledgebase and perhaps provide guidance to innovative research options. We need to explore more creative options and methodologies which can be used appropriately in these areas. What we have at the moment is not adequate for the future.

In conclusion, I am making a plea for proper, evidence-based information to be prepared *with* consumers. Consumers also need to be properly recompensed for this work. I sit on many committees where I and my fellow consumers are the only ones who are not being paid. We need training for consumer reps and people who will assist in the preparation of information and support for them in the work, so that consumers can maintain a consumer perspective in an often challenging environment. We need information to be provided in as many formats as possible through mechanisms that are accessible - if the web is to be used more widely, we need better public access strategies. Internet kiosks at

public facilities or in health centres would be one option and access to someone trained to help people learn how to use the technology.

In the Healthwise Healthy Communities Project in Idaho, consumer focus groups were run to teach people how to use the handbook, website and call centre in their search for health information. We need strategies like this to ensure that consumers really are empowered by the evidence to make better health care decisions. This is the perhaps the last great untapped resource for health - the power of informed consumers to use good evidence to determine appropriate health care and service models for themselves. We need to look at consumer reporting of health effects (good and bad) and take these reports more seriously. If you think consumers don't trust the health system, just look at how little the health system trusts the experience of consumers!! Imagine a different future where we collected and analysed such experiences in large numbers and treated them seriously as triggers, possibly, to more formal traditional research.

Such a change requires a shift in the power relationships in health care which is fairly fundamental and extremely challenging to health professionals and the health system. My theory about clinician comfort in the provision of information is that most are happy to provide a patient with sufficient information to agree with the clinician's decision. This is not consumer empowerment - it is merely paternalism dressed up in a more modern guise. Empowered consumers will question and disagree with their health care provider from time to time when they have looked at the best evidence available - and that is how it should be. Consumers' issues, concerns and experiences must be taken seriously, even if they are outside the clinician's own paradigm.

Building a better evidence base for health care delivery

Carolyn McNally

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Health Insurance Commission*

Today I want to talk to you about the use of evidence in health care from a different perspective by demonstrating how information derived from health care utilisation patterns can be used to inform best practice, health care planning and informed health care decision-making.

There is no doubt amongst any of us here today that there is a growing demand for information in all aspects of the health care sector, whether this is for the purposes of providing health care, assessing health care delivery and its performance, or planning new approaches to health care. The quest for information that is occurring throughout the health care sector is our attempt to be not only better informed, but the best informed. Clearly, we would all like all the information at our finger tips but this approach leaves us with an issue of trying to work our way through mountains of available information before we find the information we actually need and are looking for.

Those of us involved in providing information need to consider:

- what information;
- for what purpose;
- how it will be accessed; and
- by whom.

By addressing these issues pro-actively we will need to try different approaches to building an evidence base.

Evidence for health care purposes traditionally arises from undertaking clinical research such as randomised clinical trials. There is now increasing emphasis on social research and evaluation methodologies as health care combines medical and social approaches to care to meet the varying needs of individuals. A number of new evidence-based approaches and opportunities for information are now being explored. These opportunities include making use of existing data sets and integrating this information with best practice approaches to care, so that the maximum health care benefits and outcomes can be achieved.

One of these approaches is taking advantage of existing data sets. This means a number of issues need to be considered. The data being accessed need to be relevant for the context of the decision, take into account the processes against which a decision is made and anticipate the outcomes of decisions as a result of the information provided. Additionally, the data needs to be accessible and useable, that is it needs to be available as value adding information rather than indiscriminate sets of data.

One of the major data sets available in relation to health care in Australia is the data held by the Health Insurance Commission (HIC).

The HIC manages a wide range of Government health programs which means that it manages a large volume of individual and population data on health service utilisation.

Programs administered by the HIC currently amount to over 11 billion dollars in health care expenditure annually. Payments in 1998/1999 included:

- Medicare (\$6.6 billion)
- Pharmaceutical Benefits Scheme (\$3 billion)
- Veterans' Treatment Accounts (\$1.1 billion)
- Private Health Insurance Incentives Scheme (\$128 million)
- Practice Incentives Program (\$127 million)
- Commonwealth Childcare Rebate (\$116 million)
- Australian Childhood Immunisation Register (\$103 million)
- Hearing Services Program (\$103 million)

As a consequence of its administration of these programs, the HIC has accumulated a wealth of data that could be used more effectively to assist in decision making to improve the health of the Australian community. Demand for HIC information is beginning to rise and as demand increases it needs to become available for dissemination through a number of channels. For example, in 1999/2000 almost 8.5 million telephone enquiries were received through the HIC's call centres, and the HIC received over 7,500 requests for data extraction. In the first 11 months following the establishment of a new dynamic interactive HIC statistical public Internet site, over 19,000 customised statistical reports were generated by users.

Changes in information technology and information management are dramatically reshaping the way in which the HIC undertakes its traditional business and are also opening up new opportunities to use the information gained to assist decision-making without compromising the privacy or confidentiality of personal information.

HIC information as a community asset

As demand for access to HIC-held information grows, the HIC has formed a number of partnerships with key stakeholders. By consulting widely, collaborating in joint ventures and forming these key partnerships, the HIC is putting in place mechanisms to make the data it holds available as information. Work to date includes a range of disease management trials, health information trials and working with stakeholders to help them gain a better understanding about the data we hold, including its limitations. To facilitate this activity we are developing a range of electronic prototypes based on using the World Wide Web as an enabler.

The consultative forums established to date include:

- **Consumer Advisory Committee (CAC)**

The CAC provides advice on a wide range of consumer issues, including projects to support consumer health care decision making and the applicability of HIC data and other resources to the improvement of health outcomes. Committee membership is drawn from 12 key consumer organisations such as the Consumers' Health Forum, the Carers' Association of Australia, the Council on the Ageing and the National Aboriginal Community Controlled Health Organisations.

- **Divisions' Advisory Committee (DAC)**

The DAC provides an essential link between Divisions of General Practice, their State based organisations and the HIC. The Committee will help develop, implement and evaluate information management resources to support the work of Divisions and general practice and design a range of integrated information products. Its membership includes representatives from Divisions of General Practice and their state based organisations, the Commonwealth Department of Health and Aged Care and the Health Insurance Commission.

A series of web based information products are being developed to meet the needs of Divisions of General Practice and their State-based organisations. These products provide Divisions with direct access to aggregated health information held by HIC.

Clinical Advisory Groups

Three Clinical Advisory Groups (covering cancer, vascular disease, and diabetes):

- provide expert clinical advice to the HIC on information to support best practice and national policy in specific health priority areas;
- advise on how the HIC data can best be used to support clinical practice, including comparisons of actual clinical practice against best practice guidelines; and
- advise on development of tailored and relevant information products and services.

Membership comprises general practitioners, specialists and relevant government representatives. In consultation with Clinical Advisory Groups, the HIC will be looking at how to use HIC data to provide information to medical practitioners and others about how current practice compares with national guidelines on best practice. Over the next twelve months, work is expected to be completed on providing information on the treatment of diabetes, and substantially advanced on information products relating to the treatment of asthma.

HIC information focus

The HIC's information focus has 5 major components, which include:

- protecting personal privacy recognising the HIC has advanced security systems and a good track record in this regard;

- data quality as the completeness and accuracy of information is critical to forming a better evidence base;
- data warehousing to make information more accessible to suit varying needs;
- information products and services so that information is tailored to individual needs; and
- utilising a variety of information access channels.

Current Information Product development focuses on 4 major areas: consumers; Divisions of General Practice; disease management products for providers to enhance best practice; and coordinated care.

In respect of consumer focused information, recent research undertaken by the HIC in partnership with the Consumer Advisory Committee revealed a high level of interest in:

- information that relates to an individual;
- location of providers;
- enabling consumers to play a role in protection of their own information;
- ensuring that by making information more accessible there are better safeguards than those that exist in a paper environment; and
- utilising information derived from health service utilisation not only for provider based disease management but to support consumer friendly disease management approaches for those consumers wishing to take a pro active role in their own care.

Divisions of General Practice are interested in using de identified HIC information to support needs assessment, and health service program planning to target their activities appropriately and for evaluation of improved health outcomes. Examples include gaining a greater understanding about:

- distribution of general practitioners by postcode;
- Medicare and Pharmaceutical Benefits Scheme expenditure by Division, by postcode and the top items dispensed; and
- implications of new government initiatives such as the take up of the Enhanced Primary Care items and eligibility for annual health assessments (ie where the patients over 75 are located by postcode) and the Medicare cost of providing annual health assessments to these patients.

As highlighted earlier in my discussion on Clinical Advisory Groups, HIC information is being assessed to enable doctors to assess best practice on an individual basis. By providing doctors with a better understanding of the numbers of persons in their practice with specific diseases (which we derive by assessing tests and pharmaceutical use and providing this information in a de-identified form but matched against best practice benchmarks) doctors are able to assess how their patients are going. For example diabetes management can be improved if the doctor knows about insulin use, eye tests, HBA1c, lipids and microalbumin ordering patterns. Providing this information regularly enables the doctor to prompt him or herself to ask their cohort of diabetes patients about their status in this regard.

For more information and examples about the use of HIC information please visit the HIC web site at www.hic.gov.au/statistics.

In summary using information from densely populated data sets such as those held by the HIC, has the potential to assist in a more informed health care sector and bring about a better evidence base. To achieve this the value of this information needs to be recognised and valued as an important community asset.

USING AND MANAGING NATIONAL ADMINISTRATIVE DATA

The WA linked database: the use of population-based record linkage for health services research

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The word 'quality' could well be seen as the catchcry of the 1990s in the Australian health industry. The assessment of outcomes and participation in quality assurance is now a requirement in clinical activity. It has generated an industry in quality assurance, much of which has little relevance to clinicians and does not contribute to evidence-based medicine or influence clinical behaviour.

The Rogers vs Whitaker case, in which blindness occurred as an adverse complication following eye surgery, ultimately led to the Tito review of the Australian health care industry. The Report of the review; 'Compensation and Professional Indemnity in Health Care' also led to the 'Quality in Australian Health Care Study'. The Report took five years to produce and contains 168 recommendations. The report is concerned with improving 'safety' and the 'quality of care' provided by all sections of the health care industry and stipulates that the current drive for 'efficiency' must be matched by a drive for safety and quality.

Recommendations in the Report include:

- the identification of adverse events and the development of mechanisms for their prevention;
- provision of accurate information for both providers and consumers, and the legal accountability of the industry to the consumer;
- methods to encourage best practice including clinical trials, outcome research, development of clinical guidelines, medical ethics and the importance of reviewing all clinical activity;
- funding only being provided in return for appropriate consumer information, maximum health gain, minimising cost and ongoing performance monitoring of services; and
- patient access to their records.

One of the most difficult challenges to the use of good quality health information to support health care planning decisions, is the many different levels at which critical analysis needs to occur. At one extreme there are the broadly defined general trends in health status of the population while, at the other extreme, we have the highly technical and specific investigations of the efficacy, effectiveness and cost of a particular, well-defined health intervention under highly controlled conditions. Somewhere in between lies an entity known as 'outcomes research', characterised by non-experimental design, a

focus on utilisation of services and/or outcomes for patients, and the research use of administrative databases. Increasingly, we must develop a facility to move between the different layers of the Chinese boxes, made of these multiple levels of analysis. It is pointless and practically impossible to evaluate every health care intervention using a randomised experiment. The big picture is lost and there are practical and cost limitations to what can be evaluated experimentally. Besides, how well an intervention performs under controlled conditions is not always how well it will perform under diverse conditions within a complex health system. On the other hand, a preoccupation with the big picture alone lacks the focus and detail needed for meaningful incremental change.

We must become facile in moving between the different levels in the system of Chinese boxes, directing the focus of our planning and evaluation efforts appropriately, and according to the crux of the matter under consideration. There are times when an outcomes research approach is best; at others times a clinical trial is needed, or possibly, a broader social and demographic analysis of the situation. Each level of analysis has its distinct profile of advantages and disadvantages relative to another level. The importance of outcomes research was highlighted in the Report 'Compensation and Professional Indemnity in Health Care'. The advantages of outcomes research compared to clinical trials is that it is less expensive; is based on actual practice (effectiveness); is the method of choice for safety research; studies system side effects (economics); allows the study of marginal effects of the shift in practice; and often involves longer term outcomes.

In keeping with the model, the WA Health Services Research Linked Database (WA Linked Database) has been developed under the direction of Professor D'Arcy Holman, Professor Ian Rouse, Associate Professor Michael Hobbs and Dr John Bass as an infrastructure tool for health services research. The WA Linked Database was commissioned in 1996 and consists of population-based hospital morbidity data, birth and death records, mental health services data, cancer registrations and midwives' notifications, linked back to 1980 and containing around 8-9 million records. An important feature of the WA Linked Database is that all specific patient identifiers are removed prior to the start of any research to maintain patient confidentiality. The Linked Database is unique in Australia and is one of only four other such databases in the world (based at Oxford, Rochester, Manitoba and Scotland). It is also planned to link up other Commonwealth data sets such as the Pharmaceutical Benefits Scheme and the National Death Index, and other important State-based research databases and the WA electoral roll.

The next part of my presentation concerns the initial results of a statewide review of colorectal cancer in WA. The review was carried out as part of the Quality of Surgical Care Project, which was established to review the outcomes of surgical care for all of WA.

In keeping with the recent focus on evaluating outcomes of surgical procedures at a community level, the Quality of Surgical Care Project was established in June of last year to evaluate surgical outcomes in Western Australia (WA). The Project is a collaborative

venture among the Royal Australasian College of Surgeons (WA Branch), the Department of Public Health (Centre for Health Services Research, University of WA) and the State Health Department. The specific aims of the Project are to describe the epidemiology of selected diseases requiring surgical care; monitor trends in the utilisation of surgical procedures; evaluate the outcomes of new and established surgical interventions; establish benchmark standards for outcomes of surgical care; and finally, to recommend and evaluate the implementation of appropriate changes in clinical practice to improve the quality of surgical care in WA and to disseminate the results to the consumers, providers and policy makers of surgical care.

A population-based study of the incidence, mortality and outcomes following surgery for colorectal cancer in WA (1982-95)

Study aims: The specific aims of this study were to use a population-based linked database to:

- review the incidence and mortality outcomes for colon and rectal cancer in WA between 1982 and 1995; and
- assess the morbidity and mortality for surgical management of colon and rectal cancer in WA between 1988 and 1995.

Background: Colorectal cancer is a leading cause of morbidity and mortality in the Western World. In WA, colorectal cancer is the third most common cancer and approximately one in 19 males and one in 29 females will develop the disease by the age of 75 years. While the literature contains many reports on the management of colorectal cancer from single institutions or groups of specialist surgeons, there are few data on community-wide patterns of treatment or the outcomes of colorectal surgery.

In this study, the WA Linked Database was used to identify all patients with colorectal cancer that are registered in the State Cancer Registry and then to link all hospital and death records for all patients with a diagnosis of colorectal cancer in 1982-95. These linked records were then used to identify patients who were surgically treated for colorectal cancer. The index admission for each patient was defined as the hospital episode in which the first surgical treatment for colorectal cancer occurred.

Case selection: The ICD-9-CM diagnosis codes used for the selection of patients included two groups: those first diagnosed with malignant neoplasm of the colon (153.0 to 153.9, excluding 153.5, malignant neoplasm of the appendix); and those first diagnosed with a malignant neoplasm of the rectum (154.0, 154.1, excluding malignant neoplasms of the anal canal and anus, 154.2, 154.3, 154.8). Due to inconsistencies between the procedure codes in the ICD-9 and ICD-9-CM classification systems, procedure records were only obtained from 1988-95.

Nine ICD-9-CM procedure groups were used to identify patients who were surgically treated with right hemicolectomy (45.73), resection of transverse colon (45.74), left hemicolectomy (45.75), sigmoidectomy (45.76), other partial excision of the large intestine (45.79), total intra-abdominal colectomy (45.8), other pull-through resection of

rectum (48.49), abdominoperineal resection of rectum (48.5), and anterior resection of the rectum with or without synchronous colostomy (48.62 and 48.63 combined). The first six codes (45.73 – 45.8) were used to define the group of colon procedures, while the latter codes (48.49 – 48.63) identified rectal procedures. In 53 cases, both colon and rectal procedures were carried out during the index admission. These people were classified as rectal cases.

General Results (1982-95): A total of 9,673 cases of primary colorectal cancer were ascertained in the WA State Cancer Registry in 1982-95. Two thirds (65%) were colon cancers. The mean age for diagnosis of colorectal cancer was 68 ± 13 years and was similar for men and women. While the proportion of men and women diagnosed with colon cancer was similar, a higher proportion of men were diagnosed with rectal cancer. Crude frequency: The 60-74 year age group had the highest crude frequency of cases and deaths from colorectal cancer, although the 75+ year age group had the highest age-specific incidence and mortality rates.

Age-standardised annual incidence and mortality for colon and rectal cancer. Most incidence and mortality rates were fairly stable over the 14-year period. The two exceptions were an average annual increase of 1.6% ($P < 0.05$; Poisson regression) in the age standardised incidence rate of rectal cancer in men, and an average annual increase of 1.5% ($P < 0.05$) in the mortality rate of women from colon cancer. These results are similar to the general results reported by Bell et al (1997) for NSW.

Relative survival: Survival analysis of patients diagnosed with colorectal cancer was carried out using relative survival with the use of a SAS computer program developed by the Mayo Clinic but modified to include annual life table data for the WA population (1980-96), from the Australian Bureau of Statistics. The advantage of this method is that it provides an objective measure of the proportion of patients dying from the direct or indirect consequences of disease corrected for the effect of other causes of death. Hence, relative survival refers to the ratio of survival observed in a given patient population compared with the survival expected on the basis of age and sex-specific mortality rates in the general population.

Around 4% of cases were first diagnosed at the time of death. The relative survival of colorectal cancer patients continued to decline for the first five years after index admission to about one half of that expected on the basis of background population rates. After five years, the relative survival of patients with colorectal cancer remained stable at around 55% and increased slightly after ten years presumably due to a healthy survivor effect. There was no difference in the survival outcomes for men or women.

Outcomes of surgical management: A total of 4 794 patients (71.4% of patients diagnosed with colorectal cancer) were surgically treated for the first time for colon or rectal cancer in WA in 1988-95. Of these, nearly 70% of patients were treated for carcinomas of the colon. The mean and median lengths of stay for patients treated surgically were around two weeks and were similar for the two cancers. While 29% of patients with colon cancer were admitted for emergency treatment, only 12% of patients

with rectal cancer were admitted in this way. The number of patients who died during the index admission was less than 5% in both the colon and rectal groups. However, the 30-day mortality for colon cancer (4.7%) was higher than in rectal patients (3.1%; $P = 0.04$, $\chi^2 = 4.4$ DF = 1).

Procedures: Including procedures performed after the index admission, there were a total of 5 165 surgical procedures for colorectal cancer in WA in 1988-95, of which 70% were for carcinoma of the colon. The majority (95%) of procedures were carried out at the time of the index admission. Right hemicolectomy was the most common colon procedure followed by sigmoidectomy and left hemicolectomy. These three procedures accounted for 84% of all procedures used to investigate and treat colon cancer. Anterior resection of the rectum (with or without synchronous colostomy) was the most frequently performed rectal procedure (65%), followed by abdominoperineal resection (34%). The percentage of sphincter saving operations increased slightly from 61% (100/165) in 1988, to 65% (134/206) in 1991, and to 71% (154/216) in 1995.

Of all patients treated surgically for colorectal cancer, 6.5% had a coded complication of anastomotic leakage within 30 days of separation, the majority of whom were returned to theatre. Anastomotic leakage was more common following procedures for rectal cancer than colon cancer (9.7% cf 5.7%).

Relative survival following surgery: There was no difference observed in the survival of patients with colon or rectal cancer, and while men had a better survival rate than women, the differences were not statistically significant.

Problems: One principal weakness of a linked database is that the information requires validation. While internal validation of data from the Cancer Registry, Hospital Morbidity Database System and the Death Registry provides an initial strength of the WA Linked database, a complementary program of chart review is currently being established. A comprehensive system of ongoing validation of these types of databases will support appropriate interpretation of the data. In this study we had access to a group of 477 patients whose files were independently audited and the results validated. Staging of the cancer was determined in all patients and showed that 63% of colon cancers and 55% of rectal cancers were first diagnosed at advanced stage disease.

In conclusion, this study represents a unique use of population linked data to review incidence, mortality and outcomes following surgery for colorectal cancer across an entire community. The results of this study demonstrate that colorectal cancer is a disease of considerable public health importance in WA with increases in the incidence rate of rectal cancer in men and the mortality rate of colon cancer in women. Too many patients are presenting with advanced disease or as emergency cases. The absence of any improvement in the outcomes of surgical intervention for the disease lends support for an effective community-based screening program for the preventive management of the disease.

Using and managing national administrative data: a clinical classification perspective

*Associate Professor Rosemary Roberts
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The University of Sydney*

Introduction

Coding of clinical data is a prerequisite for translation of health data into meaningful information. This process requires clinical input to the definition of terms, their application and interpretation of the coded output. In this sense, what is commonly known as 'administrative' data is in fact clinical data. The codes and their definitions provide a common language so that clinicians and administrators understand the meaning of information about health and utilisation of health services.

Not only does the coding of clinical terms provide a bridge of understanding between users of health data, it is a technical foundation for the creation of an electronic health record. Without the ability to express words in a commonly understood format, information about consumers' health and their use and experience of health services cannot be stored, transmitted and analysed by health professionals. A classification such as ICD-10-AM (Australian Modification), which contains statistical categories based on a rich foundation of clinical terms, provides the wherewithal for electronic health record development.

Clinical data

The ICD-10-AM classification system provides a coding structure for a range of clinical elements. They include reasons for visit, symptoms, signs, diagnoses, external cause, place of occurrence and activity relating to injury, complications (including adverse events), surgical procedures and other interventions. Submission of coded data from hospitals goes to make up the State and national morbidity data set which in turn is used for a range of purposes including the monitoring of utilisation of health services, national burden of disease, epidemiological trends, research and funding of hospitals.

As mentioned in the introduction, ICD-10-AM contains in its tabular list statistical categories which may relate to a commonly occurring disease or groups of diseases or symptoms. The tabular list is organised primarily according to body system and site, although some chapters such as Infectious Diseases, Oncology and Injury relate to aetiology. The procedure classification is also structured according to system and site, with further specificity depending on procedure type.

For both diseases and procedures, there is an extensive index of clinical terms relating to the tabular list groupings. This index, organised according to World Health Organisation International Classification of Disease convention, is a rich source of clinical terms. It

aims to be exhaustive of all terms used in clinical medicine and surgery, albeit phrased as they are within the conventions of ICD expression.

In terms of granularity of the concepts within ICD-10-AM, these index terms are at the finest level. The tabular list represents grouping of these terms. The Australian Refined Diagnosis Related Groups are a higher level again of grouping of diseases and procedures which can be further bundled according to Major Diagnostic Category.

Each of these levels of granularity has to be considered in the use and management of clinical data.

Users and managers of clinical data

These include:

- Clinicians
- Clinical coders and health information managers
- Consumers
- Administrators
- Funders
- Bureaucrats
- Epidemiologists

Needs of users

Diagnosis and procedure coding allows the reflection of patient characteristics and treatment during an episode of acute in-patient care. An understanding of codes and the conventions and standards that govern their choice is necessary to ascribe meaning to health data. It is also important that the processes for collecting data be efficient and accurate. The multiple uses of data collected does, however, place pressure on the codes and the coding process. The need to have a common understanding of the meaning of codes for casemix grouping was one of the main reasons that the National Centre for Classification in Health (NCCH) was created in 1994.

Standards

NCCH contributes to national and international standards through the funding of its core activities by the Commonwealth Department of Health and Aged Care. The National Health Information Management Group ratifies successive editions of the classification for publication and has recently created an Expert Group on Health Classifications following recommendations from the Electronic Health Records Taskforce and endorsement by Australian Health Ministers in July. It also uses the World Health Organisation ICD classification and conventions as a basis for the ICD-10-AM classification which is the Australian standard for use for acute hospital in-patients. NCCH is advised by members of the Coding Standards Advisory Committee in developing the Australian Coding Standards which are published as part of the ICD-10-AM classification and guide coders and users of coded datasets. Appropriate definitions

from the Australian Coding Standards are mirrored in the National Health Data Dictionary (eg principal diagnosis, procedure).

Other Australian and international standards are applied through NCCH membership of Standards Australia and International Organisation for Standardisation (ISO) health informatics committees on vocabularies and semantics and health concept representation.

All these connections are in fact two way, with Australia not only applying standards developed elsewhere but contributing its expertise to the content and application of standards.

ICD-10-AM

The ICD-10-AM (Australian Modification) classification is the NCCH flagship. Its content has been converted to an Access database, which allows easy maintenance and clinical update of the classification for successive editions. NCCH works closely with the Department of Health and Aged Care in managing its codes in relation to refinements of the Australian Diagnosis Related Groups. While the current focus is on coding for acute episodes of care, recent work on ambulatory coding is setting the scene for a classification to be used across an episode of illness. The Australian Coding Standards are used to educate clinical coders in application of the codes, and NCCH provides support for coders through its website and organisation of coding queries in an Access database. The centre's products are in hard copy and electronic format, with the ICD-10-AM database providing a foundation for electronic products of the whole or part of the classification. Other software products emanating from NCCH include measures of coding quality inputs (Australian Coding Benchmark Audit) and outputs (Performance Indicators for Coding Quality).

Clinical input to the classification for the codes themselves, terms and connection with casemix grouping is provided by 23 specialty groups of clinicians and clinical coders. Members of these groups, nominated by the Australian Casemix Clinical Committee and the NCCH, are consulted frequently in relation to classification update, use of terms and education material. This interaction with clinicians at a national level reflects the relationship between coders and clinicians at the hospital level, so that coders can correctly interpret the documentation in the medical record and clinicians can understand the structure of the classification.

Routine coding at the point of care is still some distance away, especially in hospitals. However, the availability of the classification as a database means it can be included in software applications used, for example, in operating theatres and emergency departments. Coding close to the event by those with access to most detail can only assist the clinical coder to code accurately all aspects of care following patient discharge. Terms used in coding can be matched with those used in MesH headings, creating a natural bridge for clinicians between the use of diagnosis and procedure terms and accessing clinical guidelines and medical literature.

Terminologies

NCCH is creating a terminology based on terms used in the tabular and index of ICD-10-AM. The inclusion of ICD-10-AM in the Unified Medical Language System (UMLS) of the National Library of Medicine in the USA has assisted in this process of defining terms and linking them to the concept unique identifiers (CUIs) of the metathesaurus. These identifiers provide links with other classifications and terminologies included in the metathesaurus such as SNOMED, ICPC, NHS Clinical Terms, LOINC and nursing classifications.

Definitions

While definitions of how to apply codes are included in the Australian Coding Standards and the National Health Data Dictionary, ICD-10-AM itself is not a dictionary, but does contain limited definitions of diseases and procedures. Within the ICD-10 'family' of classifications, especially in mental health, there are specific guidelines and criteria for allocating codes and sometimes specific classifications for specialty areas such as neurosciences and oncology. The Australian Coding Standards contain some definitions of clinical terms where clarification is required for coders and some clinical and physiological criteria for assigning codes, for example chronic renal failure and impairment, diabetes and anaemia. The procedure classification within ICD-10-AM has fine-grained distinctions in terms and codes according to procedure site, type, approach, use of prostheses and other information such as staging.

Severity

ICD-10-AM is not a classification of functional impairment. It does contain some codes relating to physical ability, continence and activities of daily living, but does not attempt to classify function and disability in the comprehensive coverage of measures such as the Uniform Data Set Functional Independence Measure (FIM) or the International Classification of Functioning and Disability (ICIDH). The latter is also part of the WHO Family of Classifications.

Codes from ICD-10-AM are used by the Australian Refined Diagnosis Related Groups (AR-DRG v4.1) as additional diagnoses to distinguish patient complication and comorbidity level (PCCL).

Specific severity measures such as the Abbreviated Injury Scale (AIS) use ICD-10-AM codes from different body systems to reflect severity of injury. Other diseases such as asthma and epilepsy have severity splits within ICD-10-AM codes and descriptors.

Coordination

Use of classifications such as ICD-10-AM is coordinated with fields in the national minimum data set as defined by the National Health Data Dictionary published by the

Australian Institute of Health and Welfare. This discipline is also necessary for attaching codes to clinical protocols and guidelines, complications and outcomes of care.

By virtue of using ICD-10 as a basis for the ICD-10-AM classification, the morbidity collection from acute hospitals is coordinated with the mortality collection managed by the Australian Bureau of Statistics which codes cause of death in ICD-10. The relationship is strengthened within NCCH which is a joint venture between the University of Sydney (NCCH Sydney, primarily responsible for morbidity coding and funded by the Department of Health and Aged Care) and Queensland University of Technology (NCCH Brisbane, primarily responsible for mortality issues and funded by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics).

Input to and use of the classification is also coordinated with a number of specialty areas, including cancer and chronic disease registries, the perinatal collection, waiting list systems, audit and risk management systems and reporting of incidents and adverse events. ICD-10-AM includes codes for adverse events, including complications of medical and surgical care and misadventures.

Above all, ICD-10-AM values the input to its activities from the clinical coders who apply the codes, from clinicians who create the source documents and from users of coded data sets at the hospital, state and territory and national levels.

Mappings

Creation of mappings between different versions of the ICD-10-AM classification and with other classifications is an important part of NCCH work. Historical mappings are created for use of longitudinal studies involving coded data sets, while logical mappings allow use of a range of classifications for casemix groupings build on a particular classification or version of a classification. Mapping is an inherently imperfect science in that most relationships involve one to many mappings, and forward and backward mappings may not synchronise. However, mappings (or crosswalks as they are sometimes called), despite their flaws, are extremely useful in allowing the building blocks of care episodes to be cemented together to form episodes of illness or to describe health and health intervention for an individual or community over a period of time.

The inclusion of ICD-10-AM in the UMLS metathesaurus referred to earlier is an important advance in that it allows mapping between terms and codes in ICD-10-AM to concepts which in turn can be translated to the way in which those concepts are represented in other classifications held in the metathesaurus. This mapping to a common identifier helps to overcome some of the blurring inherent in direct mapping and provides a discipline of equating special terms to a commonly agreed concept in a logical hierarchy of terms. Such an explicit use of hierarchies in turn allows mappings to various levels of specificity according to data use.

Electronic health records

Codes are a means of representing health concepts in an agreed way. They provide a common understanding of the language of health. Because concepts are currently extracted from hard copy narrative health records for coding purposes, the use of codes to reflect concepts is an important foundation on which to build electronic health records and allow analysis and exchange of concepts between such records. Work is underway in many countries to develop clinical terminologies or vocabularies so that 'entry terms' can be interfaced with 'reference terms' for coding purposes. NCCH intends to use its rich index of terms in ICD-10-AM as the basis for an Australian Clinical Vocabulary so that a strong connection is maintained between use of terms and representation of term by code. The centre is maintaining its links with overseas work through WHO and ISO and other forums related to health informatics and health record management.

Conclusion

A complex network of coding systems, educated coders, informed clinicians and Australian Coding Standards allows the collection of data on diseases and procedures as a by-product of information in the patient health record. Clinical (or administrative) data gathered in this way is an extremely rich source of valuable information about our nation's health and the way in which Australians use health services.

Standards for data collection and maintenance developed through NCCH provide a guarantee of quality and the basis for measurement of compliance with good coding practice.

NCCH also provides an interface between creators and users of data so that codes and standards are pertinent and the process of coding and extraction are as efficient as possible.

The infrastructure developed by NCCH builds on a long tradition of medical record systems and coding in Australian health services. This provides a strong foundation and the required expertise to build electronic health records efficiently and to allow their use as a dynamic force in improving Australia's health.

Health outcomes research using national administrative data – a new era

Dr Chris Kelman

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With the increasing collection of data in electronic form, there is a common perception that big brother can and does examine the intimate details of our lives.

Now this may be the case if you want to know about shopping preferences or credit ratings, but if you want to examine health care outcomes it is quite a different story. Although large quantities of health service data are collected by the states and Commonwealth, it is not generally used for research - for two main reasons, firstly because it is seriously lacking in clinical detail and secondly, because it is almost impossible to get access to it.

If you want clinical detail, you will have to use paper records, this is also a challenge, these records are stored in the well known 'distributed paper database', of multiple health establishments and protected by the strong encryption protocol of doctor's handwriting.

It is quite surprising how we continue to spend 8% of GDP on health care services without knowing how effective they are and without keeping a record even of who has had them. For example, the fact that there is no registry of implantable medical devices is not generally known, if a product recall is required, as has happened several times in the last few years, the only way to contact patients is to advertise in the media. It was this fact that inspired me to examine our national health service datasets and see whether it was possible to use them for health outcomes research.

Today I'll discuss some of the reasons why so little has been done with these datasets for health care evaluation and research, and then what we need to do to improve this situation now that a more enlightened age is dawning. My perspective comes from personal experience in trying to use our national data both as an academic researcher and now as an employee of the Department of Health and Aged Care. I have experienced problems in both capacities, albeit slightly different ones.

The HIC keeps records of all services covered under the MBS, and also for around 30% of PBS claims. Unfortunately little clinical detail is contained in the majority of the MBS claims, often just an indicator for the length of the consultation is collected.

When combined, these databases store information about almost every doctor visit, service, hospital admission and death occurring across the country. Most of this data is collected for financial purposes, but as a fringe benefit creates the best record of health service use that we have.

It should be noted that although the States collect comprehensive hospital data, and are able to use this for research, they do not have direct access to MBS and PBS data which makes it rather difficult for them to generate a complete picture of health care. This situation is an unfortunate consequence of the structure of our health system, where funding is provided from both State and Federal budgets.

The States' admissions datasets contain records of all public and private hospital admissions, along with Casemix and ICD codes - these datasets are amalgamated at the AIHW. The resulting NHMDS is the most significant health research database in the country, but unfortunately, under State health acts for each jurisdiction, records must be de-identified before submission to the AIHW. The rationale for this is that the States should not reveal personal information about patients to the Commonwealth. I am not sure who benefits from this, but the result is a kind of data-vandalism. An information resource that could be of considerable public health benefit is emasculated.

Each of the private health insurers collects accurate and complete information about their members, and in the USA, many important studies have been performed using this type of data collected by their HMOs. However, this resource has been little used in Australia.

Although the idea of using electronic data collections for research may seem appealing, there are many limitations and a number of barriers which have held back this sort of research. I will describe the different problems that confront the researcher depending on whether the project is conducted outside or within the Department.

The most significant barrier for the non-government or academic researcher is the requirement for individual patient consent before access to the various datasets is allowed. This process is time consuming and costly, but in addition, it introduces selection bias thus undermining the accuracy of any results.

Due to the number of data custodians, multiple ethics committees must be consulted for a national research project: despite the fact that the AIHW manages the NHMDS, approval from each of the States is still required before use of the data is allowed - this is a surprising situation and further limits the attractiveness of this resource for research. In my recent data linkage project at the Australian National University, I was required to seek approval from 12 ethics committees. It took around 18 months to complete this process. Again, such delays are costly for research projects. One has to be fairly devoted to the cause to pursue this type of data!

A major problem for the academic researcher is how to select a cohort of patients. A complex situation exists because of the need for individual patient consent.

This is a 'Catch 22' situation - information is required about patients' medical history in order to know who to ask to consent to be part of the study. However such information is not available from the national data repositories without *prior patient consent*.

Because of this requirement for consent before obtaining access to the data, the establishment of cohort studies is difficult to say the least!

In my study, I was fortunate to be able to gain assistance from Medibank Private. They agreed to provide me with a list of patients who'd had the chosen treatments and to write to them asking for their consent to be part of the study - thus I acquired a cohort. Cohort selection of course is another important benefit that could arise from a national health network. It would be very productive to be able to readily select a group of subjects with a common health problem and to examine their health outcomes, compare treatment effectiveness and costs, investigate drug adverse events and so on. All this could be achieved with a specially prepared, de-identified file that protects the identity of the people involved.

Various serious biases are introduced when the current arrangements involving patient consent and third parties are used. Several biases were considered in my study of implantable medical devices- of necessity all consenting patients were privately insured, but those that consented were more likely to be those that were still alive and those that had good outcomes. These biases reduce the power and value of this type of research. It is questionable whether the personal benefits of 'strong' privacy protection are worthy of the community loss in terms of public health information.

It doesn't have to be this hard - for example in Canada, data about health care is actually collected for the dual purposes of paying providers and health service evaluation. I was able to perform a parallel study in Manitoba - what took 18 months in Australia took three weeks in Winnipeg. Their system actually encourages research.

For example, **Ethics approval** required one application to one committee, approval was given within three weeks.

Data collection was simple, each person had a UPI and all services were recorded electronically. After signing the appropriate security and confidentiality agreements, the process took about two weeks in the Winnipeg office.

A significant advantage of the Manitoba data apart from its availability is that there is no selection bias and no response bias - all patients that had the chosen procedures were enrolled and no personal contact was required.

One would expect that the Commonwealth Department of Health would be in a prime position to utilise these national datasets for the benefit of community health - to evaluate programs, detect adverse events, perform cost-effectiveness studies of treatments, monitor performance of new interventions.

In fact, it could be argued that the Department would be irresponsible to not perform this work - the public would surely expect that all treatments are monitored and that only the most effective are funded.

Sadly, this is not the case and it is only recently that these data resources have begun to be utilised for the purpose of evaluation. The Departmental researcher has certain advantages over the academic, for example for Departmental research projects, there is the option of seeking Ministerial approval to use the MBS-PBS data - this avoids the requirement for both individual consent and ethics approval (as long as personal identifiers are not supplied). However, there are other time-consuming barriers to overcome before data can be utilised. Extensive contracts must be drawn up between the various data custodians and involvement of the Privacy Commissioner is required.

In each of the three projects that we have under way at present more than two years were spent negotiating, preparing instruments for the release of data and drafting agreements.

There are a number of changes that will be necessary to support the use of health service data for health outcomes evaluation and monitoring.

Many of these initiatives are incorporated in the recently released report *A Health Information Network for Australia* and it is the introduction of HealthConnect that will at last allow the rational use of health data for the purpose of providing an evidence base for health care.

I will review some of the major features of the proposed network that will be crucial for the research use of service data.

First, a national system is required to ensure lifetime coverage and uniform standards for the collection and distribution of data. The report proposes the following:

- National standards for the collection and transmission of health care data
- An electronic health record
- A unique patient identifier (UPI)
- Communication infrastructure for national access
- Security measures

All of these features are essential for the collection and management of health care data for individual patient management and will produce significant improvements in quality of care and a reduction in the rate of adverse events.

Electronic health records will in addition provide the potential for a quantum leap improvement in the quality and availability of health service data. Unless we devise a means to make this resource available for health outcomes research and monitoring, adverse event detection, product registers and so on, we will, in my opinion, be missing an unprecedented opportunity.

To do this however, some additional controls will be required to ensure appropriate use of the data and appropriate protection of the privacy and dignity of the population. Whatever we do, it will be necessary to win the support of the community - the proposed system is after all, an 'opt in' system.

It will be important to publicise *the benefits* of using health data for research to provide the base for evidence-based medicine and for quality assurance in health care.

There will be a need for a national body to oversee research projects using this new data resource (it is needed right now to manage various projects planned with existing data, John Bass will talk more about ways of managing this problem).

An independent national research review committee would be charged with the task of ensuring that our national networked health data would be used for the most appropriate and productive purposes, it could provide both methodological and ethical review of research proposals and manage permission to access the data. It would also assess researcher credentials and ensure the observance of security and privacy requirements.

This committee would fall most comfortably under the NHMRC or perhaps even the Office of the Federal Privacy Commissioner. It could become an additional function of the proposed HealthConnect access control authority. It constitutes a public health initiative and thus should logically be funded by the Department of Health and Aged Care, however some independence may publicly be seen to be an advantage.

To summarise

We are on the eve of an exciting new era in health information management, and we need to take some pro-active steps to manage these new resources.

We need to take the task of public education seriously, it will be crucial to get the word out that health care can be improved and made more safe with HealthConnect, that not only will your health records be accurate and available but that your experiences will contribute to the knowledge base of medicine while your privacy is maintained. Development of the legislation and mechanisms to achieve this will of course be necessary!

It will be optional to participate, but to do so should be considered to be an advantage.

Thanks everyone for listening, I hope I have managed to inspire you with the potential of a new era in health care!

Using and managing national administrative data

Dr John Bass

Health Insurance Commission

Abstract

The Health Insurance Commission is working towards providing its health information as a resource for the health sector to use in planning and research. Preserving the privacy and confidentiality of health records is obviously a top priority. The success of joint projects also involves the sharing of data from more than one source. Generating the necessary trust between organisations requires a procedure that allows each data custodian to retain adequate control over their own records while still providing planners and researchers with the appropriate combined data sets.

WHERE IS E-COMMERCE HEADING IN HEALTH?

E-commerce in health

Ms Susan Medlin

Manager, Strategy Management Team, Victorian Department of Human Services

Abstract

Through the explosion of the Internet, e-commerce technologies and models are having a revolutionary impact on all industries involved in business-to-business relationships. There have been several studies undertaken overseas and within Australia which all conclude that there are significant opportunities for the health industry to capture benefits from the information exchange and leverage intrinsic to trading in an e-procurement environment.

Health Online recognised the need for a national approach to advancing the use of e-commerce in supply chain activities in the health care system. Action Item 6.1.1 refers to activities that would support this goal. On 16 June 2000, NHIMAC endorsed the establishment of the Health Supply Chain Reform Taskforce. Taskforce membership includes representatives from State and Commonwealth governments, supplier industry, private and public hospitals. The first meeting was held on 26 July 2000.

E-commerce in health

Mr Phil Dibben

National Councillor, Pharmacy Guild of Australia

Abstract

With new access options the definition of 'community' is changed forever. Geographic access is only one dimension. A community may be based upon involvement in:

- the wellness community worldwide;
- a treatment program based around the pre-eminent hospital in the country; and
- a preventative program linking all of my health provides and my insurance provider.

Consumer's expectation of health professionals are also changing:

- better informed consumers demand better informed health professionals.
- exposure to easy 24-hour a day, 7-day a week access in other areas creates similar pressures in health provision.

Participants at the National *Health Online* Summit

Dr John Ainge	President and Chief Executive, Officer Atmedica Asia Pacific
Dr Jane Aitken	Department of Health and Aged Care
Dr Daryel Akerlind	Director, Prometheus Information
Mr Jenk Akyalcin	T/IM Training and Support Consultant, General Practice Divisions Victoria
Mr Vlad Aleksandric	Executive Director, ACT Department of Health and Community Care
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